# Investigating third-party functioning and third-party disability in family members of people with aphasia

**Meghann Jane Grawburg**

BHSc (honours)

MSc

A thesis submitted in partial fulfilment of the requirements for the degree of

Doctor of Philosophy

School of Communication Disorders

College of Science

University of Canterbury

New Zealand

October 2013

# DECLARATION BY AUTHOR

I certify that this thesis is composed of original work and does not contain any material previously submitted for a degree or diploma in any university; and that to the best of my knowledge and belief it does not contain any material previously published or written by another person except where due reference is made in the text. I have clearly stated the contribution by others to jointly-authored works that I have included in my thesis and the contribution of others to my thesis as a whole, including data analysis, editorial advice, statistical assistance, survey design, and any other original research work used or reported in my thesis.

I also certify that the research reported in this thesis has been approved by the appropriate institutional ethics review boards, including: the University of Canterbury Human Ethics Committee, the New Zealand Health and Disability Ethics Committee, and the Behavioural and Social Sciences Ethical Review Committee at the University of Queensland, Australia.

Meghann Grawburg Date: 9/10/2013

# ACKNOWLEDGEMENTS

Completion of my PhD thesis has absolutely been a team accomplishment. I am so fortunate to have had the encouragement, support, and confidence of many people throughout my journey. I am incredibly grateful to each of you.

First of all, I would like to express my deepest appreciation to my exceptional team of supervisors who have imparted inspirational passion for their research and a zest for life. Thank you, Nerina, my mentor for how to combine PhD studies and having babies, for your contagious can-do attitude and for sharing your expertise in all things third-party disability. Thank you, Linda, for listening, for connecting me with other helpers around the globe, and for keeping me mindful of the bigger picture. And to Tami, charged with the task of being my primary supervisor, thank you for providing meticulous feedback and careful direction in balance with warm personal encouragement throughout my PhD journey. I especially appreciate your teaching me to take a breath and take another look and, perhaps most significantly, for sticking with me through earthquakes, aftershocks, moves, pregnancies, and babies. The last four years sure have been full of adventure!

I would like to acknowledge the statistical assistance of Dr. Chi-Wen Chien, who was never too busy to help with Rasch analysis. A big thank you to my translators, Sandra Wielaert, Martina Schaefer, Franziska Stuewe, and Elizabeth Gibson. Thank you also to Eleanor Barclay, Lucy Schumacher, and UC librarian Patrician Jordan for their help with the systematic reviews, Felicity Bright for sharing her expertise about hope, Associate Professor Barbara Grant for her methodological teachings, Associate Professor Pierre Pluye for advice regarding methodological

quality rating, and Professor Alan Tennant and Professor Brian O'Connor for their guidance in statistical analysis.

My sincere appreciation goes out to all of the people with aphasia and their families for opening their homes and their hearts to share their stories of aphasia. Your participation made this research possible! I am indebted to many speech therapists and speech pathologists, in New Zealand and Australia, for participant referrals and help with data collection. I am particularly thankful to Freya Davison, Mary Cronin, Dr. Kyla Brown, Dr. Clare McCann, and The Aphasia Registry: Communication Disability Centre at the University of Queensland. I never would have made it to 100 (and beyond!) without you.

Thank you to so many of the postgraduate students and staff at the University of Queensland and the University of Canterbury, especially the Creyke Road gang. Special thank you to my counterpart at the University of Auckland, (almost Doctor) Karen McLellan, for alternately listening with compassion, talking sense into me, and/or pacifying me with chocolate, as required.

To my family and friends in all corners of the earth, thank you for your thoughts on the beta version of the SOS-Aphasia, for never being afraid to ask about how my PhD was coming along, and for cheering me on every step of the way. Thank you to my parents for their unrelenting belief in me, especially my Mum whose voice I can always hear in my head, saying "*... think you can, or you think you can't... you are right.*" (Also thank you to Henry Ford for that one).

I have been so lucky to have the two cutest research assistants ever. Finn, thank you for your enduring charm and good behaviour as we travelled over 5500 kilometres, from the bottom of the South Island to the top of the North Island, on our data collection missions. Summer, my mini Rasch expert, thank you for sleeping in

the front pack while I type and cooing quietly during skype meetings (usually). Most of all, thank you both for keeping it all in perspective.

I have reserved the jump-up thank you for my husband, best friend, and number one supporter. Jacek, thank you for doing this with me. Like so many things in our lives together, my PhD has been an adventure with ups and downs that have affected you as much as me, so much so that we have come to call its effects "third-party PhD". Thank you for all of your technical support: programming the website and the ICF generator, writing code for sorting the database search results, learning SPSS syntax and R then teaching them to me, making diagrams that look pretty and avatars that have transparent backgrounds; thank you for parenting while I presented at conferences and most weekends while I wrote; and, thank you for your financial support. Most of all, thank you for your unrelenting love and belief in me. You have always said that dreams are for doing and have backed it up each day with your actions. Thank You. ILU.

Along with the funding provided by my generous, hard-working husband, I am appreciative of the financial contributions from a College of Science scholarship at the University of Canterbury, a scholarship from the Tavistock Trust for Aphasia, and a research grant from the New Zealand Speech-Language Therapists' Association.

*~ Meghann Grawburg*

# ABSTRACT

Due to the profound impact that aphasia has on both the person with aphasia and their close family members, aphasia is a family problem. Aphasia is a communication disorder, most commonly caused by stroke. It is associated with impairments in spoken language, understanding, reading, and writing that impact upon daily activities, participation in society, and the quality of life of those with the condition and their family members. However, family-centred rehabilitation programs, policy, and funding are not well established.

In the International Classification of Functioning, Disability and Health (ICF), the World Health Organization introduced the term "third-party disability" and identified the need for further investigation into family members' functioning and disability in relation to a significant other's health condition. In this thesis, the term "third-party functioning" is used to describe positive and/or neutral changes to a family member's functioning as a consequence of a significant other's health condition; "third-party disability" describes negative changes. The overall aims of this thesis are to: i) describe third-party functioning and disability in family members of people with aphasia post-stroke, and ii) develop the Significant other Scale for family members of people with Aphasia (SOS-Aphasia), a scale for measuring third-party functioning and third-party disability in this population.

Two systematic reviews were conducted to provide a summary of the current literature related to family members' third-party functioning and third-party disability secondary to aphasia. Positive/neutral and negative findings were extracted from included articles, then synthesized and mapped to the ICF. These reviews showed that family members experienced third-party functioning and third-party disability secondary to aphasia in the Body Functions and Activities and Participation components of the ICF, in addition to the development and exacerbation of health conditions. The results laid the groundwork for the qualitative-quantitative sequential mixed methods study that followed.

In the first phase of the study, qualitative methods were used to explore the positive and negative effects of aphasia on family members, thus expanding and confirming our existing understanding of third-party functioning and third-party

disability. Twenty family members participated in individual in-depth semi-structured interviews, which were analysed using qualitative content analysis with research codes subsequently mapped to the ICF. The results revealed five categories of positive/neutral aphasia-related changes, including: (1) emotions (e.g., focusing on the positive); (2) communication (e.g., talking to the person with aphasia more); (3) relationships (e.g., making new friends); (4) recreational activities and social life (e.g., taking up new hobbies); and (5) paid/volunteer work or education (e.g., volunteering to help people with aphasia). In addition, seven categories that described the negative effects of aphasia on family members were revealed: (1) physical, mental, and emotional health (e.g., tired); (2) communication (e.g., difficulty communicating with the person with aphasia); (3) relationships (e.g., lack of physical intimacy between spouses); (4) recreational activities and social life (e.g., restricted social activities); (5) paid/volunteer work or education (e.g., took extended time off work); (6) domestic and caregiving responsibilities (e.g., transporting the person with aphasia places); and (7) finances (e.g., loss of person with aphasia's income). Research codes were mapped to two domains within the Body Functions component (i.e., Mental functions and Functions of the digestive, metabolic and endocrine systems) and eight domains within Activities and Participation components of the ICF (i.e., Learning and applying knowledge, General tasks and demands, Communication, Self-care, Domestic life, Interpersonal interactions and relationships, Major life areas, and Community, social and civic life). Health conditions (e.g., depression and anxiety) associated with the aphasia of a significant other were also identified in family members. Mapping of the qualitative research codes to the ICF demonstrated how the ICF framework could be applied to family members.

The second phase of the study involved the development and validation of the SOS-Aphasia. The SOS-Aphasia items were derived from the constructs of third-party functioning and third-party disability identified in the qualitative study and the response scale format was based on the ICF. Following the development of the SOS-Aphasia, 104 family members completed the original 34-item version. Factor analysis and Rasch analysis were used to examine the underlying structure and internal construct validity of the SOS-Aphasia. Test-retest reliability and feasibility were also investigated. Based on the analysis, five SOS-Aphasia subscales were identified and

10 items marked for deletion. The revised 24-item SOS-Aphasia demonstrated preliminary evidence of good psychometric properties.

In summary, this series of studies demonstrates that family members experience third-party functioning and third-party disability, as well as changes to their health, secondary to a significant other's aphasia. In addition, the SOS-Aphasia shows validity and reliability in measuring third-party functioning and third-party disability. Together, these findings provide the motivation for the inclusion of family members of people with aphasia in a family-centred care model with implications for research, practice, and policy.

# PUBLISHED WORKS BY THE AUTHOR INCORPORATED INTO THE THESIS

The following refereed journal publications have emanated from the work presented in this thesis:

1. Grawburg, M., Howe, T., Worrall, L., & Scarinci, N. (2013). Third-party disability in family members of people with aphasia – A systematic review. *Disability and Rehabilitation, 35(16):* 1324-41.

2. Grawburg, M., Howe, T., Worrall, L., & Scarinci, N. (2012). A systematic review of the positive outcomes for family members of people with aphasia. *Evidence-Based Communication Assessment and Intervention, 6*(3), 135-149.

3. Grawburg, M., Howe, T., Worrall, L., & Scarinci, N. (2013). A qualitative investigation into third-party functioning and third-party disability in aphasia: Positive and negative experiences of family members of people with aphasia. *Aphasiology, 27*(7), 828-848.

*4*. Grawburg, M., Howe, T., Worrall, L., & Scarinci, N. (2013). Describing the impact of aphasia on close family members using the ICF framework. *Disability and Rehabilitation*. Advance online publication. doi: 10.3109/09638288.2013.834984

Note: Proof of permission to reproduce these articles in a PhD thesis is provided in Appendix B.

# CO-AUTHORSHIP FORM 1

Deputy Vice-Chancellor's Office
Postgraduate Office

UNIVERSITY OF CANTERBURY
*Te Whare Wānanga o Waitaha*
CHRISTCHURCH NEW ZEALAND

## Co-Authorship Form

This form is to accompany the submission of any thesis that contains research reported in co-authored work that has been published, accepted for publication, or submitted for publication. A copy of this form should be included for each co-authored work that is included in the thesis. Completed forms should be included at the front (after the thesis abstract) of each copy of the thesis submitted for examination and library deposit.

Please indicate the chapter/section/pages of this thesis that are extracted from co-authored work and provide details of the publication or submission from the extract comes:

Grawburg, M., Howe, T., Worrall, L., & Scarinci, N. (2013). Third-party disability in family members of people with aphasia – A systematic review. *Disability and Rehabilitation, 35(16):*1324-41.

This article has been inserted into **Chapter 2** as accepted for publication by the journal and updated with additional references (published between August 11, 2011 and September 1, 2013). Tables and figures have been embedded in the text; and references are presented at the end of the thesis. Figures and table numbers, as well as, headings and page numbers, have been adjusted to maintain consistency throughout the thesis.

Please detail the nature and extent (%) of contribution by the candidate:

Grawburg was responsible for 85% of this paper. Her role included searching the databases, assessing articles for inclusion, extracting findings from the included articles, assessing the quality of each included article, mapping findings to the ICF,

and writing the paper. Howe was responsible for assessing articles for inclusion, extracting findings from the included articles, assessing the quality of each included article, reviewing drafts, and editing. Worrall was responsible for assessing articles for inclusion, extracting findings from the included articles, mapping findings to the ICF, reviewing drafts, and editing. Scarinci was responsible for reviewing drafts and editing.

**Certification by Co-authors:**

If there is more than one co-author then a single co-author can sign on behalf of all

The undersigned certifies that:

- The above statement correctly reflects the nature and extent of the PhD candidate's contribution to this co-authored work
- In cases where the candidate was the lead author of the co-authored work he or she wrote the text

Name: Dr. Tami Howe Signature: Dr. Tami Howe Date: 9/10/2013

# CO-AUTHORSHIP FORM 2

Deputy Vice-Chancellor's Office
Postgraduate Office

UNIVERSITY OF CANTERBURY
*Te Whare Wānanga o Waitaha*
CHRISTCHURCH NEW ZEALAND

## Co-Authorship Form

This form is to accompany the submission of any thesis that contains research reported in co-authored work that has been published, accepted for publication, or submitted for publication. A copy of this form should be included for each co-authored work that is included in the thesis. Completed forms should be included at the front (after the thesis abstract) of each copy of the thesis submitted for examination and library deposit.

Please indicate the chapter/section/pages of this thesis that are extracted from co-authored work and provide details of the publication or submission from the extract comes:

Grawburg, M., Howe, T., Worrall, L., & Scarinci, N. (2012). A systematic review of the positive outcomes for family members of people with aphasia. *Evidence-Based Communication Assessment and Intervention*, *6*(3), 135-149.

This article has been inserted into **Chapter 3** as accepted for publication by the journal and updated with additional references (published between August 11, 2011 and September 1, 2013). Tables have been embedded in the text; and references are presented at the end of the thesis. Table numbers, as well as, headings and page numbers, have been adjusted to maintain consistency throughout the thesis.

Please detail the nature and extent (%) of contribution by the candidate:

Grawburg was responsible for 90% of this paper. Her role included searching the databases, assessing articles for inclusion, extracting findings from the included articles, assessing the quality of each included article, mapping findings to the ICF, and writing the paper. Howe was responsible for assessing articles for inclusion,

extracting findings from the included articles, assessing the quality of each included article, reviewing drafts, and editing. Worrall was responsible for assessing articles for inclusion, extracting findings from the included articles, mapping findings to the ICF, reviewing drafts, and editing. Scarinci was responsible for reviewing drafts and editing.

**Certification by Co-authors:**

If there is more than one co-author then a single co-author can sign on behalf of all

The undersigned certifies that:

- The above statement correctly reflects the nature and extent of the PhD candidate's contribution to this co-authored work
- In cases where the candidate was the lead author of the co-authored work he or she wrote the text

Name: Dr. Tami Howe Signature: Dr Tami Howe Date: 9/10/2013

# CO-AUTHORSHIP FORM 3

Deputy Vice-Chancellor's Office
Postgraduate Office

UNIVERSITY OF CANTERBURY
*Te Whare Wānanga o Waitaha*
CHRISTCHURCH NEW ZEALAND

## Co-Authorship Form

This form is to accompany the submission of any thesis that contains research reported in co-authored work that has been published, accepted for publication, or submitted for publication. A copy of this form should be included for each co-authored work that is included in the thesis. Completed forms should be included at the front (after the thesis abstract) of each copy of the thesis submitted for examination and library deposit.

Please indicate the chapter/section/pages of this thesis that are extracted from co-authored work and provide details of the publication or submission from the extract comes:

Grawburg, M., Howe, T., Worrall, L., & Scarinci, N. (2013). A qualitative investigation into third-party functioning and third-party disability in aphasia: Positive and negative experiences of family members of people with aphasia. *Aphasiology*, *27*(7), 828-848.

This article has been inserted into **Chapter 4** as accepted for publication by the journal. Tables have been embedded in the text; and references are presented at the end of the thesis. Table numbers, as well as, headings and page numbers, have been adjusted to maintain consistency throughout the thesis.

Please detail the nature and extent (%) of contribution by the candidate:

Grawburg was responsible for 90% of this paper. She was primarily responsible for the design of the study, participant recruitment, data collection, analysis and interpretation, reviewing and updating the literature review, and writing the paper. Howe, Worrall, and Scarinci contributed to the design of the study, data

analysis and interpretation, reviewing drafts and editing.

**Certification by Co-authors:**

If there is more than one co-author then a single co-author can sign on behalf of all

The undersigned certifies that:

- The above statement correctly reflects the nature and extent of the PhD candidate's contribution to this co-authored work
- In cases where the candidate was the lead author of the co-authored work he or she wrote the text

Name: Dr. Tami Howe Signature: Date: 9/10/2013

# CO-AUTHORSHIP FORM 4

Deputy Vice-Chancellor's Office
Postgraduate Office

UNIVERSITY OF CANTERBURY
*Te Whare Wānanga o Waitaha*
CHRISTCHURCH NEW ZEALAND

## Co-Authorship Form

This form is to accompany the submission of any thesis that contains research reported in co-authored work that has been published, accepted for publication, or submitted for publication. A copy of this form should be included for each co-authored work that is included in the thesis. Completed forms should be included at the front (after the thesis abstract) of each copy of the thesis submitted for examination and library deposit.

Please indicate the chapter/section/pages of this thesis that are extracted from co-authored work and provide details of the publication or submission from the extract comes:

Grawburg, M., Howe, T., Worrall, L., & Scarinci, N. (2013). Describing the impact of aphasia on close family members using the ICF framework. *Disability and Rehabilitation*. Advance online publication. doi: 10.3109/09638288.2013.834984

This article has been inserted into **Chapter 5** as accepted for publication by the journal. Tables have been embedded in the text; and references are presented at the end of the thesis. Table numbers, as well as, headings and page numbers, have been adjusted to maintain consistency throughout the thesis.

Please detail the nature and extent (%) of contribution by the candidate:

Grawburg was responsible for 90% of this paper. She was primarily responsible for the design of the study, participant recruitment, data collection, analysis and interpretation, conducting the literature review, the paper. Howe, Worrall, and Scarinci contributed to the design of the study, data analysis and interpretation, reviewing drafts and editing.

**Certification by Co-authors:**

If there is more than one co-author then a single co-author can sign on behalf of all

The undersigned certifies that:

- The above statement correctly reflects the nature and extent of the PhD candidate's contribution to this co-authored work
- In cases where the candidate was the lead author of the co-authored work he or she wrote the text

Name: Dr. Tami Howe Signature:  Date: 9/10/2013

# LIST OF PRESENTATIONS BY THE AUTHOR RELEVANT TO THE THESIS

The following presentations have been delivered at national and international conferences during the candidature period:

Grawburg, M., Howe, T., Worrall, L., & Scarinci, N. (2012). Use of qualitative interviews with family members to describe third-party disability in aphasia. *International Aphasia Rehabilitation Conference*, Melbourne, Australia, 7-10 October 2012.

Grawburg, M., Howe, T., Worrall, L., & Scarinci, N. (2011). Third-party disability in aphasia: Qualitative interviews with family members linked to the ICF. *The World Report on Disability: Implications for Asia and the Pacific,* Sydney, Australia, 5-6 December 2011.

Grawburg, M., Howe, T., Worrall, L., & Scarinci, N. (2011). Third-party disability in aphasia: Family members report how they have been affected by having a relative with aphasia. *Aphasia Association of NZ Biennial Conference, Rotorua,* New Zealand: 16-18 November 2011.

Grawburg, M., Howe, T., Worrall, L., & Scarinci, N. (2011). Third-party disability in aphasia: Qualitative interviews with family members categorized according to the ICF. *8th Asia-Pacific Conference on Speech, Language and Hearing, Christchurch,* New Zealand: 11-14 January 2011.

Grawburg, M., Howe, T., & Worrall, L. (2010). Third-party disability in aphasia: What do we know about the experiences of family members? *International Aphasia Rehabilitation Conference*, Montreal, Canada (Poster Presentation): 27-29 June 2010.

* The presenting author is shown as underlined

# KEYWORDS

aphasia, third-party disability, third-party functioning, ICF, family members, caregivers, stroke

# TABLE OF CONTENTS

# LIST OF FIGURES

# LIST OF TABLES

# CHAPTER 1

## AN INTRODUCTION TO THIRD-PARTY FUNCTIONING AND THIRD-PARTY DISABILITY IN APHASIA

---

*"Families find themselves in difficulty after a member of the family has a stroke. I consider myself a stroke survivor but my family are stroke victims…"*

– Casey (WHO, 2011, p. 94).

## 1.1 APHASIA SECONDARY TO STROKE

In the Western Pacific region, which includes New Zealand and Australia, cerebrovascular disease is the leading cause of burden of disease, an indicator of mortality, disability, and loss of health due to a particular condition (WHO, 2008). The incidence of stroke in this region is estimated to be 3.3 million per year with approximately 9.1 million people living with stroke-related disability (WHO, 2008). Stroke or other injury may cause damage to the language areas of the brain and result in aphasia, which is associated with difficulty speaking, understanding, reading, and writing, with implications for daily activities, participation in society, and the quality of life of those with the condition, and their family members. Approximately 30-35% of people with stroke will present with aphasia in the acute stages (Dickey, et al., 2010; Engelter, et al., 2006; Kauhanen, et al., 2000) and for 60% of those who experience aphasia post-stroke, it becomes a chronic condition (Pedersen, Vinter, & Olsen, 2004). Assisting people with aphasia and their family members to adapt to communication difficulties has been identified as a top priority in stroke research (Pollock, St. George, Fenton, & Firkins, 2012).

## 1.2 THE IMPACT OF APHASIA ON FAMILY MEMBERS

Aphasia certainly has an impact on the everyday lives of the people with the disorder, but family members are also affected (Michallet, Tétreault, & Le Dorze, 2003). Research conducted over the past 45 years has revealed extensive negative consequences of aphasia on family members impacting their health and daily lives. Some studies have suggested that family members of people with aphasia experience more problems than those of people with stroke without aphasia (Herrmann, Britz, Bartels, & Wallesch, 1995; Kinsella & Duffy, 1978). More recent research has also shown positive outcomes for family members.

### 1.2.1 Negative effects of aphasia on family members

McKenzie Buck, a speech-language pathologist with aphasia due to stroke, is credited as being the first to refer to aphasia as a family problem (Marshall, 2002). Since he first observed psychiatric symptoms in family members of people with aphasia (Buck, 1968), a large number of studies have reported the negative

consequences of aphasia for family members. Predictably, family members experience difficulty communicating with the person with aphasia. However, family members also experience other problems secondary to aphasia. These include relationship problems (Le Dorze, Tremblay, & Croteau, 2009; Michallet, et al. 2003), an increase in caregiving duties, such as in helping with the person with aphasia communicate with others (Le Dorze & Signori, 2010), negative emotions, such as frustration and anxiety (Christensen & Anderson, 1989), reduced time for social activities (Artes & Hoops, 1976), and changes in work (Hemsley & Code, 1996), and finances (Le Dorze & Signori, 2010). Furthermore, mental health problems in family members, including depression (McGurk, Kneebone, & Pit ten Cate, 2011) and anxiety (Nätterlund, 2010) have been attributed to aphasia.

### 1.2.2 Positive effects of aphasia on family members

In addition to negative outcomes, family members of individuals with aphasia may experience positive changes to their functioning as a result of the aphasia. Post-traumatic growth refers to the positive change that sometimes occurs after a loss (Tedeschi & Calhoun, 1996). Examination of post-traumatic growth is essential in order to provide a holistic description of the effect of aphasia on family members, with particular relevance for identifying and building upon strengths to facilitate coping and rehabilitation planning (Kramer, 1997; Palmer & Glass, 2003; Saleebey, 2009). Though post-traumatic growth in family members of people with aphasia has not been thoroughly explored, a small number of positive outcomes have been demonstrated through qualitative investigation. Previous studies have shown that the relationship between the family members and the person with aphasia can improve (Michallet et al., 2003; Williams, 1993) and family members may experience personal development, such as an increase in self-confidence (Nätterlund, 2010) and a feeling of being useful (Le Dorze, et al., 2009).

## 1.3 FAMILY-CENTRED CARE IN APHASIA

The provision of family-centred care in aphasia involves collaboration between the person with aphasia, their family members, and health professionals (Kuo, et al., 2012). Family members are included in rehabilitation services, not only

as supporters of the person with aphasia, but also as clients with a need for care themselves (Visser-Meily, et al., 2006). In a model of family-centred care, family members are seen as experts and involved in all aspects of healthcare decision-making with flexible care plans, differing with respect to individual characteristics, strengths, and preferences (Kuo, et al., 2012). Supporting family members as clients improves their ability to assist the person with aphasia; thus, taking care of family members is likely to have benefits for the person with aphasia and their recovery. Conversely, people with aphasia without adequate family member support may experience greater disability and increased reliance on formal support through the healthcare system (Tate, 2009; WHO, 2011).

Despite an awareness of the difficulties that family members experience secondary to aphasia, infrastructure for the provision of family-centred care in policy and practice is limited. Code (2012) has indicated that the amount of care provided to people with aphasia and their family members is not proportional to their need, "*...aphasia has a more devastating effect upon the lives of aphasic people and their families than any other disease or disability, there is still a significant gap between these findings and the amount of time provided by for treatment."* (Code, 2012, p. 729).

### 1.3.1 Barriers to the implementation of family-centred care

Several potential barriers exist to the inclusion of family members of people with aphasia in family-centred care. One barrier could be the nonspecific terminology used for describing family member outcomes, such as caregiver burden and quality of life (Greenwood, Mackenzie, Cloud, & Wilson, 2008; Visser-Meily, Post, Riphagen, & Lindeman, 2004). Though these terms are commonly used, there is limited agreement on their definition and scope; thus, they do not provide reliable information for clinicians or policy-makers. Similarly, though there are a plethora of generic measurement tools for assessing family member outcomes, many researchers have indicated the need for a specific tool for family members of people with aphasia (Herrmann, 1997; Le Dorze & Brassard, 1995; Le Dorze, et al, 2008; Michallet, et al., 2001; Rigby, Gubitz, & Philips, 2009; Rombough, Howse, & Bartfay, 2006).

Another barrier, related to existing policy, could be insufficient funding allocated for the inclusion of family members in rehabilitation (Levack, Siegert, Dean, & McPherson, 2009), which may be more costly in the short-term (Kuo, 2012). At the clinical level, family members are not routinely assessed when measuring and reporting outcomes in aphasia (Simmons-Mackie, Threats, & Kagan, 2005), nor are family members frequently included in intervention programs (Brown, Worrall, Davidson, & Howe, 2011; Michallet, Le Dorze, & Tétreault, 2001). Speech-language pathologists do not often have goals for family members of people with aphasia (Sherratt, et al., 2011), and have indicated that they have limited time and resources for providing family intervention (Dalemans, de Witte, Wade, & van den Heuvel, 2010; Johansson, Carlsson, & Sonnander, 2011; Law, et al., 2010). As a tool intended for use in research, social policy, and clinical practice, the International Classification of Functioning, Disability and Health (ICF) may help to overcome these barriers by facilitating a clear, consistent description of the functioning and disability of family members (Threats, 2010; WHO, 2001).

## 1.4 AN OVERVIEW OF THE ICF

The World Health Organization's (WHO) ICF is an internationally recognised framework for describing health and health-related states from a biopsychosocial perspective (WHO, 2001). In the field of speech-language pathology, applications of the ICF include the development of policy supporting evidence-based practice (Ma, Threats, & Worrall, 2008), construction of assessment tools and measures of intervention efficacy (Worrall & Hickson, 2008), as well as classification of an individual's functioning and disability secondary to aphasia (Simmons-Mackie & Kagan, 2007).

The ICF provides a common language and structure for conceptualising how interactions between an individual's Health Condition and Contextual Factors are associated with changes to their Functioning, Disability and Health. The first part of the ICF is called Functioning and Disability; it includes the components of Body Functions and Structures, and Activities and Participation. Positive and/or neutral aspects of Functioning are described in terms of Body Functions and Structures, Activities, and Participation. Negative aspects of functioning are labelled Disability

and described in terms of Impairments, Activity Limitations, and Participation Restrictions. The second part of the ICF is called Contextual Factors and includes the components of Personal Factors and Environmental Factors (WHO, 2001). Figure 1 displays the ICF model, which illustrates the relationship between an individual's Health Condition, Contextual Factors, and their Functioning and Disability.

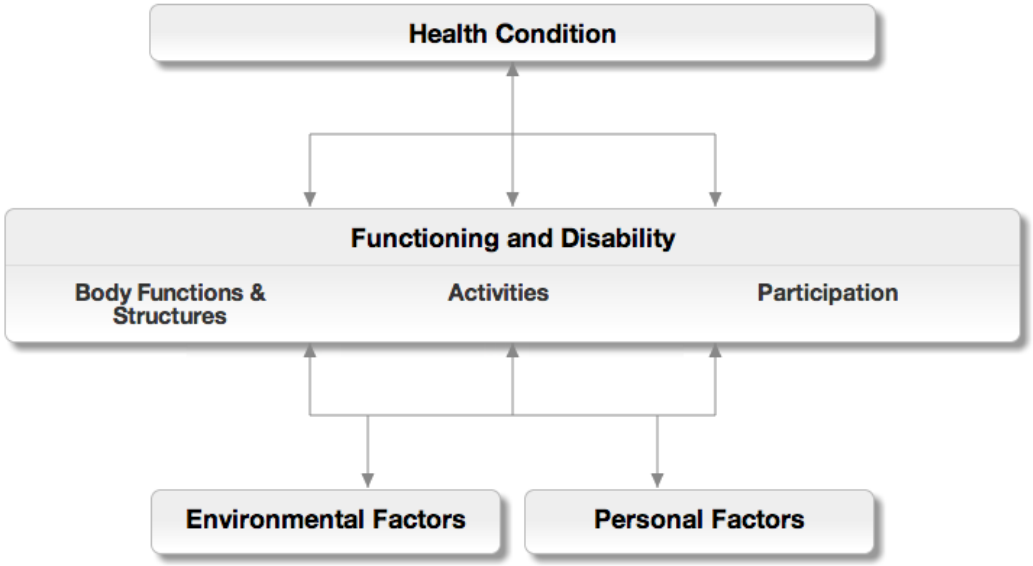


Figure 1.1. The International Classification of Functioning, Disability and Health (ICF) (WHO, 2001).

Each ICF component is further subdivided into domains corresponding to aspects of Body Functions, Body Structures, or Activities and Participation. For example, the Activities and Participation component contains the domains of Learning and applying knowledge, General tasks and demands, Communication, Mobility, Self-care, Domestic life, Interpersonal interactions and relationships, Major life areas, Community, social and civic life. Each domain contains a list of category names and corresponding codes, which can be used to further categorise an individual's Functioning. An example of a category code that applies to an individual with aphasia who has difficulty comprehending verbal communication would be 'd310 Communicating with-receiving-spoken messages.' The ICF also provides qualifiers that can be used in conjunction with codes to specify the extent of the functioning and disability where 0=no problem, 1=mild problem, 2=moderate problem, 3=severe problem, and 4=complete problem (WHO, 2001).

## 1.5 THIRD-PARTY DISABILITY AND THIRD-PARTY FUNCTIONING

In the ICF, WHO introduced the term third-party disability to describe the *"... disability and functioning of family members ... due to the health condition of significant others"* (WHO, 2001, p. 251). In this thesis, the term *third-party disability* has been used to describe the negative effects of aphasia on family members. Similarly, the term *third-party functioning* has been used to indicate positive and/or neutral changes to a family member's functioning.

### 1.5.1 A model of third-party disability

Scarinci, Worrall, and Hickson (2009) developed a model of third-party disability to show how the ICF can be extended in application to significant others. The model is based on their work with spouses of people with hearing impairment; it explains how the Functioning and Disability of a person with a health condition can act as an Environmental Factor influencing a family member. More specifically, the model, displayed in figure 1.2, illustrates how the Environmental Factor of having a partner with a hearing impairment can interact with other ICF components, including the spouse's Functioning and Disability, a pre-existing Health Condition, their Personal Factors, and other Environmental Factors, to influence the development of third-party disability in the spouse. In the same way, this model can be applied to demonstrate the process of third-party functioning.

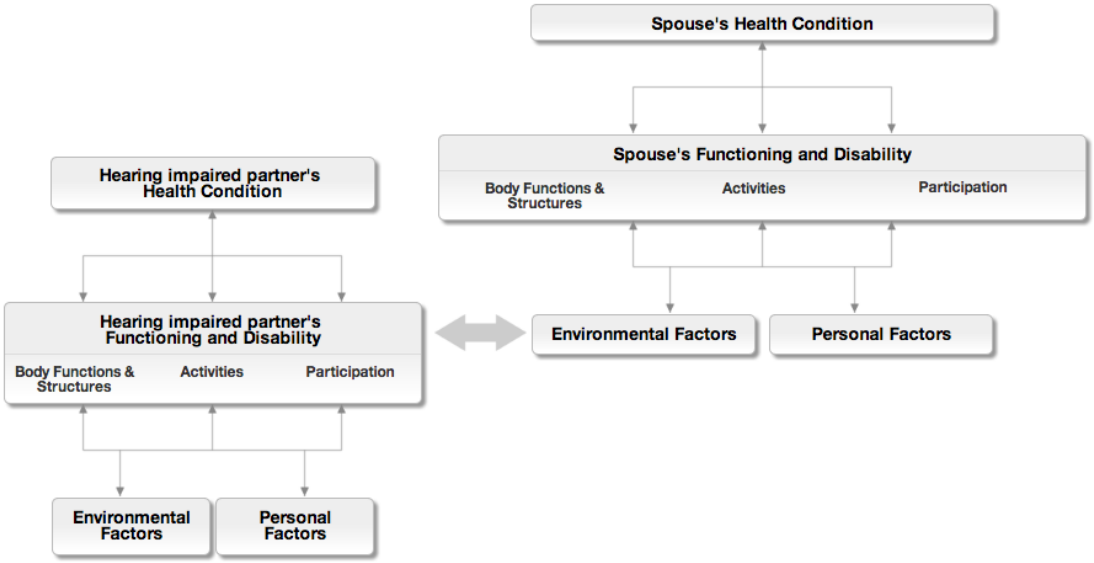


Figure 1.2. A model of third-party disability in hearing impairment (Scarinci, Worrall, & Hickson, 2009)

### 1.5.2 Third-party functioning and disability in communication disorders

A limited number of studies investigating third-party functioning and third-party disability have been conducted within the field of communication disorders. In a series of studies of spouses of people with hearing impairment, Scarinci, Worrall, and Hickson (2009, 2011, 2012) demonstrated that most spouses experience third-party disability secondary to their partner's hearing impairment. The problems experienced by spouses were mapped to the ICF domains of Communication, Domestic Life, Interpersonal interactions and relationships, and Community, Social and Civic Life (Scarinci, et al., 2009). Spouses reported that communication changes, use of communication strategies, and negative emotions associated with the hearing impairment resulted in the greatest amount of third-party disability (Scarinci, Worrall, & Hickson, 2012). Further investigation into third-party functioning and disability has been recommended in the areas of dementia (Byrne & Orange, 2005) and speech impairment (McLeod, 2006).

### 1.5.3 Third-party functioning and disability in aphasia

Despite the recognised importance of examination of this topic (Threats, 2010), scant research has been conducted to investigate third-party functioning and third-party disability in aphasia. The only study, by Le Dorze & Brassard (1995), presented the effects of aphasia on family members in the context of the International Classification of Disabilities, Impairments, and Handicaps (ICIDH) (WHO, 1980), which was the precursor to the ICF. The authors reported that family members experienced handicaps (the former conceptualisation of Participation) related to communication, relationships, supporting the person with aphasia, education, career, and recreational activities. The study of third-party functioning and third-party disability remains untouched outside the realm of communication disorders. It may be that due to the two-way nature of communication and the influence of communication difficulties on relationships, family members are more greatly affected than in other types of disorders.

## 1.6 SUMMARY

Despite years of research demonstrating the extensive impact of aphasia on family members, insufficient policy and programming exist to support them. Due to its international acceptance, common structure, and vocabulary, the ICF may best conceptualise the needs of family members of people with aphasia to facilitate communication between professionals in research, policy, and practice. Moreover, research into third-party functioning and third-party disability may provide evidence leading to improved resources and services for family members of people with aphasia (Threats, 2010), with associated positive outcomes for people with aphasia, the community, and society.

## 1.7 AIMS OF THE THESIS

The overall aims of this thesis were to describe the nature and extent of third-party functioning and third-party disability in family members of people with aphasia and to develop a scale for measuring third-party functioning and third-party disability in aphasia. The specific objectives were to:

1. Establish the current understanding of third-party functioning and third-party disability in aphasia through the completion of two systematic reviews;
2. Use qualitative methods to explore the positive and negative aphasia-related changes experienced by family members of adults with aphasia post-stroke, and to generate items for the development of a tool for measuring third-party functioning and disability;
3. Provide a description of third-party functioning and third-party disability in aphasia and justification for the application of the ICF with family members by classifying the experiences of family members of people with aphasia using the ICF;
4. And, develop and validate a tool for measuring third-party functioning and third-party disability in family members of people with aphasia.

## 1.8 AN OVERVIEW OF THE THESIS

To meet the aims and objectives of the thesis, a mixed methods investigation was conducted within the post-positivist paradigm to expose evidence that reflects the complex and interactive nature of the human experience of third-party functioning and third-party disability in aphasia (Giddings & Grant, 2007). Two systematic reviews were conducted to provide a description of the existing literature related to third-party functioning and third-party disability by synthesizing the findings of the positive and negative effects of aphasia on family members through categorisation according to the terminology of the ICF. A systematic review of the negative effects of aphasia on family members, representing the current understanding of third-party disability is contained in Chapter 2. This paper was published in *Disability and Rehabilitation* in 2013 and was updated for inclusion in the thesis with an additional four relevant papers added since the previous search date in August 2011. Chapter 3 presents a systematic review of the positive effects of aphasia on family members, representing the current understanding of third-party functioning. This paper was published in *Evidence-Based Communication Assessment and Intervention* in 2012, and was updated with the addition of one relevant paper. Studies added to these chapters after publication were screened for inclusion and assessed for quality by the candidate only since the consensus process previously developed had clearly defined the parameters for inclusion/exclusion, quality rating, and mapping to the ICF. Following from these results, a sequential qualitative-quantitative study design was implemented. This methodology was selected to provide an in-depth account of third-party functioning and third-party disability from the perspective of family members in order to expand, clarify, and confirm existing findings and provide the foundation for the development of a tool to measure third-party functioning and third-party disability (Giddings & Grant, 2009).

In the first phase of the study, 20 family members of people with aphasia participated in qualitative interviews to reveal their perspective about the positive and negative effects of a significant other's aphasia on their lives. Results were analysed using qualitative content analysis to form categories and codes, which were then classified according to the ICF. The initial qualitative results with categories derived from interviews with participants are reported in Chapter 4. This study was published in *Aphasiology* in 2013. In Chapter 5, research codes from the same study are mapped

to the ICF to provide a detailed description of the scope of third-party functioning and third-party disability in aphasia. These results provide rationale for the use of the ICF and the terms third-party functioning and third-party disability for describing family members' experience of aphasia, also discussed in Chapter 5. This paper was published in *Disability and Rehabilitation* in 2013.

Data from the first phase of the study were used to develop a tool, the Significant other Scale for family members of people with Aphasia (SOS-Aphasia), to measure third-party functioning and third-party disability in aphasia. During the second phase of the study, the SOS-Aphasia was administered to 104 family members of people with aphasia. The data from phase two were used to establish the psychometric properties of the SOS-Aphasia. In Chapter 6, SOS-Aphasia item development is explained, followed by a description of validity and reliability of the SOS-Aphasia based on factor analysis, Rasch analysis, reliability testing, and indications of feasibility.

Lastly, Chapter 7 provides a summary of the findings, including implications for clinical practice and policy. Limitations of this thesis are reiterated and discussed in the context of future research directions.

# CHAPTER 2

## THIRD-PARTY DISABILITY IN APHASIA – A SYSTEMATIC REVIEW OF THE NEGATIVE EFFECTS OF APHASIA ON FAMILY MEMBERS[1]

---

**Grawburg, M., Howe, T., Worrall, L., & Scarinci, N. (2013). Third-party disability in family members of people with aphasia – A systematic review.** ***Disability and Rehabilitation, 35(16):*****1324-41.**

[1]This chapter is an adaptation of the manuscript, entitled "Third-party disability in family members of people with aphasia – A systematic review" published in Disability and Rehabilitation in 2013 and is inserted as accepted for publication, with the exception of the addition of recent references, and modifications to the text to ensure consistency and relevance to the current chapter and thesis.

## 2.1 ABSTRACT

Background: The WHO's International Classification of Functioning, Disability, and Health (ICF) describes third-party disability as the disability experienced by significant others as a consequence of their family members' health condition (WHO, 2001).

Purpose: A systematic review of the literature was conducted to summarize the current knowledge of third-party disability in aphasia.

Method: PubMed, CINAHL and three other databases were searched for peer-reviewed studies reporting on how aphasia affects family members with no date restrictions. Findings from relevant studies that met the inclusion criteria were extracted and mapped to the ICF.

Results: This paper summarizes what is known about the experience of family members of people with aphasia, describing negative outcomes in the Body Functions and Activities and Participation components of the ICF. However, due to the limited consensus between studies, this review reveals an incomplete understanding of the nature of third-party disability.

Conclusion: While current literature suggests there is a broad range of consequences for family members of people with aphasia, the sequelae of disability for family members of people with aphasia are not well understood. Further research is needed to better describe the nature and degree of third-party disability in aphasia.

## 2.2 INTRODUCTION

Third-party disability, according to the World Health Organization's (WHO) International Classification of Functioning, Disability and Health (ICF), occurs when significant others experience disability as a consequence of their family members' health condition (WHO, 2001). The considerable influence of aphasia on the lives of family members is well known. Indeed, family members of people with aphasia have been referred to as the "hidden victims" (Threats, 2010). Research has shown that chronic aphasia can have a negative impact on the lives of family members of people with aphasia (Michallet, et al., 2003). Furthermore, aphasia has been identified as a specific factor contributing to negative outcomes for family members of people with stroke (Choi-Kwon, Hwa-Sung, Kwon, & Kim, 2005) and poorer quality of life for family members caring for people with aphasia in the second year post-stroke (White, Mayo, Hanley, & Wood-Dauphinee, 2003).

The ICF is a framework which describes health and health-related states from a biopsychosocial perspective (WHO, 2001). In the ICF, functioning, disability, and health are defined by two parts, made up of four components that interact with one another. Part one, Functioning and Disability, is composed of the Body component and the Activities and Participation component, while part two, Contextual Factors, is made up of the Environmental Factors component and the Personal Factors component. The body component includes Body Functions, which are physiological and psychological functions and the Body Structures component includes the anatomical parts of the body. In the Activities and Participation component, Activities represent individual tasks or actions and Participation is defined as involvement in life situation. Environmental Factors are physical, social, or attitudinal external influences on the individual, whereas individual characteristics such as gender and culture are identified as Personal Factors. The ICF shows how an individual's health condition can interact with contextual factors to influence their functioning and disability.

Third-party disability was identified as an area for further development in the ICF (WHO, 2001); it has since become an established concept in the field of communication disorders, particularly in hearing impairment (Scarinci, et al, 2009; Scarinci, Hickson, & Worrall, 2011; Scarinci, et al., 2012). Further investigation of

third-party disability in the area of speech-language pathology has been recommended (Worrall & Hickson, 2008), specifically for spouses of people with aphasia (Threats, 2010). Two previous studies have shown that the use of a framework such as the ICF can facilitate a better understanding of the impact of a significant other's communication disability on their family members. For example, the ICF has been used to classify the stress of family members of people with communication disorders secondary to dementia (Byrne & Orange, 2005). Similarly, Le Dorze and Brassard (1995) used the precursor to the ICF, the International Classification of Impairments, Disabilities, and Handicaps (ICIDH) (WHO, 1980) to demonstrate that family members of people with aphasia experienced changes in their communication, interpersonal relationships, responsibilities, work, and leisure activities.

Based on their research into the experience of spouses of older people with hearing impairment, Scarinci, et al. (2009) developed a model extending the ICF to explain third-party disability. An adapted version of this model, shown in figure 1, illustrates how the functioning and disability of the person with the health condition acts as an environmental factor for the family member. Specifically, the environmental factor of having a relative with aphasia ultimately has an effect on the family member's functioning, resulting in an acquired disability known as third-party disability.

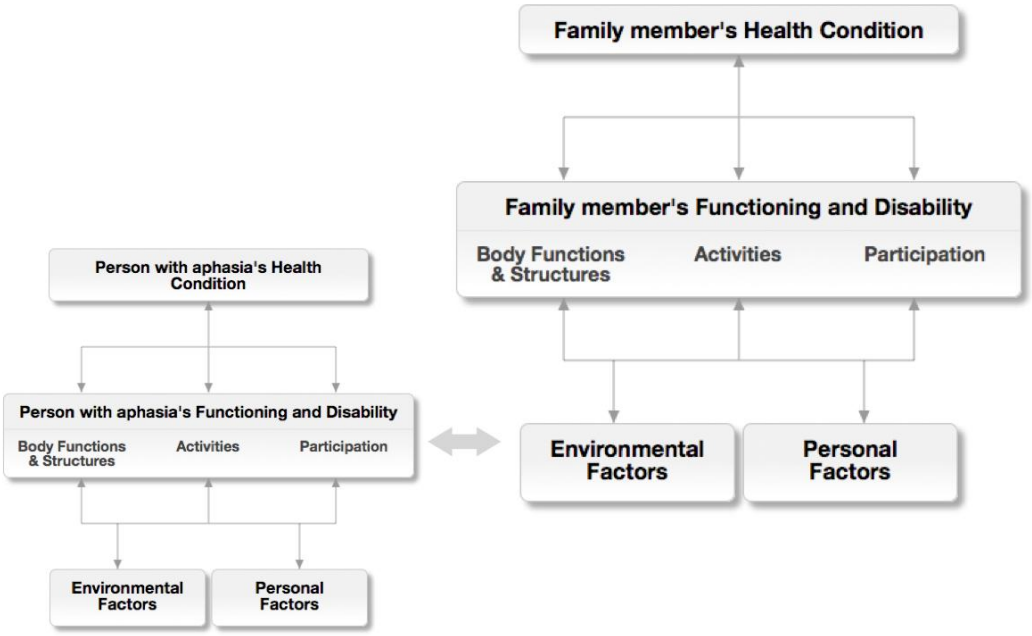


Figure 2.1. Application of the ICF to third-party disability in aphasia.

The needs of family members of people with aphasia have been indirectly acknowledged through the development and assessment of intervention programs. These programs involving family members have targeted education, emotional support, and/or communication skills training as part of their intervention (Draper, Bowring, & Thompson, 2007; Fox, Poulsen, Bawden, & Packard, 2004). Despite the known consequences of aphasia on family members and the importance of providing family-centred care post-stroke (Visser-Meily, et al., 2006), family member participation in intervention is limited as rehabilitation programs often focus on the person with aphasia with little emphasis on the consequences of aphasia on family members (Brown, et al., 2011; Michallet, et al., 2001). Previous research has identified barriers to the provision of rehabilitation services for family members, including insufficient contact time between the speech-language pathologist and family members (Dalemans, et al., 2010; Johansson, et al., 2011; Law, et al., 2010; Sherratt, et al., 2011), lack of resources for supporting family members (Johansson, et al., 2011; Law, et al., 2010; Sherratt, et al., 2011), and the need for increased clinical education, training, and experience for rehabilitating family members (Johansson, et al., 2011; Levack, et al., 2009; Sherratt, et al., 2011).

Although to date, no previous reviews have investigated the impact of aphasia on family members in relation to third-party disability, three reviews have investigated caregiver burden of family members of people with aphasia. In 1999, Servaes, Draper, Conroy, and Bowring conducted a critical review examining the stresses of caregivers of people with aphasia, though their main focus was to provide recommendations for intervention programs designed for caregivers. From the studies included in the review, the authors identified a wide variety of caregiver complaints related to aphasia including communication difficulties, role changes, depression, anxiety, physical strain, social isolation, conflict in family and marital relationships, and loss of sexual relationships. However, in many of the studies reviewed, the impact of stroke was not adequately separated from that of aphasia, making it difficult to discern how caregivers are uniquely affected by communication disabilities in the presence of other stroke-related impairments, such as physical disabilities. Guilt, overprotection, lack of time for themselves, health problems, fewer visits from friends, restricted activities, financial problems, and lack of companionship were identified as being associated with caregiver burden, but the influence of aphasia was

not specifically identified. The findings of this review were not combined to provide a cumulative description of the type of disability experienced by caregivers. Specifically, the results do not provide a clear indication of the nature of problem or the scope of the impact of aphasia on family members. In addition, as this was a critical review, it was not conducted in a systematic way and relevant studies may have been omitted.

In another review, Rombough, Howse, and Bartfay (2006) aimed to investigate caregiver burden and strain in caregivers of people with aphasia, however, their search did not reveal any articles fitting the inclusion criteria. A third review was conducted in 2007, by Rombough, Howse, Bagg, and Bartfay, to determine the appropriateness of study designs and tools for measuring quality of life in caregivers of people with stroke, with and without aphasia. Again, the systematic review did not reveal any studies that specifically isolated the effect of aphasia on caregivers.

Therefore, a systematic investigation into the experiences of family members of people with aphasia is warranted in order to provide an up-to-date summary of the literature and a clear understanding of third-party disability in aphasia with implications for rehabilitation, research, and policy. Thus, the purpose of this systematic review is to summarize the current literature describing the negative effects of aphasia on family members in the context of the ICF's definition of third-party disability. Positive effects of aphasia on family have been examined and will be presented elsewhere as a separate review.

## 2.3 METHOD

### 2.3.1 Search strategy

A systematic search of the literature within five databases (The Cochrane Library, The Cumulative Index to Nursing and Allied Health Literature, PsycINFO, PubMed, and Web of Science) was conducted from the earliest possible date as determined by the database and ending August 10, 2011. An initial search, using the terms ("third-party disability" OR "third party disability") AND (aphasia OR dysphasia) resulted in two papers being returned that addressed third-party disability in aphasia (Threats, 2010; Worrall & Hickson, 2008). Though both papers suggested that third-party disability is an important direction for further research, they did not

provide original evidence to describe third-party disability in aphasia. While the impact of aphasia on family members is widely recognized, the term third-party disability was introduced in the ICF in 2001 and this initial search showed that it is not commonly used in the aphasia literature. Consequently, it was acknowledged that published studies exist that would describe the disability associated with having a relative with aphasia, though the term third-party disability may not have been used. Thus, we undertook a second search to locate articles that describe how family members are negatively impacted by aphasia; in essence, studies that describe aspects of third-party disability without actually using the term. The following search terms and combinations were used in the second search: (family OR families OR spouse* OR carer* OR caregiver* OR son OR sons OR daughter* OR husband* OR wives OR wife OR parent* OR mother* OR father* OR sibling* OR sister* OR brother*) AND (aphasia OR dysphasia). When medical subject headings were available, they were included and combined.

Inclusion criteria:

- Describes third-party disability in aphasia. If the term third-party disability is not used, it must describe how aphasia negatively affects family members.
- Aphasia must be acquired secondary to stroke.
- Peer-reviewed studies.
- Studies must be published in English.
- Earliest date permitted by each database (CINAHL 1978, The Cochrane library 1800, PsycINFO 1890, PubMed 1966, Web of Science 1898) to September 1, 2013.
- Qualitative, quantitative, and mixed methods descriptive studies with original data.
- Family members may be described using various terminology including caregivers or carers, as long as they are unpaid.

Exclusion criteria for the first and second searches:

- Reports presented as commentary, narrative (e.g., personal stories, not analysed in a systematic way), unpublished dissertations, or conference presentations.

- Intervention studies.

- Studies that do not distinguish aphasia from other communication disorders or clearly separate the consequences of aphasia from the consequences of stroke in analysis and interpretation of findings. Due to the difficulty in attributing changes that family members experience as being solely due to aphasia, studies were selected for inclusion when the aim of the study or the methods they used were more likely to achieve this goal or when this issue was addressed in the results or discussion section. For example, qualitative studies could do this by focusing on aphasia as part of the interview guides (i.e., by asking directly about life changes associated with the aphasia) and quantitative studies could achieve this by focusing on aphasia in the way that questionnaires were administered (i.e., researchers indicating to participants that they should consider the effect of aphasia or life pre-post aphasia) or through the use of comparison groups.

### 2.3.2 Article selection

For articles published prior to August 10, 2011, multiple authors participated in article selection to reach consensus, as described in this section. Articles published between August 10, 2011 and September 1, 2013 were selected for inclusion by the candidate only, in consideration of the same criteria. The author(s) screened titles and abstracts to assess the eligibility of articles based on the research question and the inclusion criteria. Where the author(s) were unable to make a decision to reject or accept the article due to insufficient information in the title or abstract, full texts were retrieved. Full texts were then reviewed to determine eligibility for inclusion. For articles published prior to August 10, 2011, any discrepancies in the selection decisions were discussed and consensus reached. The most common reasons for exclusion were inappropriate population under study, outcome measures focusing on health and well being of person with aphasia not family members, and study design.

### 2.3.3 Methodological quality assessment of included studies

For articles published prior to August 10, 2011, the quality of each article, based on the written report, was independently appraised by two of the authors (MG and TH) with any discrepancies discussed to reach consensus. Articles published between August 11, 2011 and September 1, 2013 were screened only by the candidate, also following the procedure described here. A rating scale specifically developed for concurrent assessment of qualitative, quantitative, and mixed methods studies in the health sciences was used (Pluye, et al., 2012). The methodological quality criteria used in this scale were specific to the type of study being assessed. Qualitative studies were evaluated based on the relevance of the data sources for informing the research question, the process for analysing data, the relationship of the findings to the data, and consideration of the researchers' influence on the findings. Quantitative descriptive studies were evaluated based on the sampling strategy, the representativeness of the population under study, the types of measures selected, and the participant response rate. Non-randomized quantitative studies were evaluated based on minimization of selection bias, appropriateness of measurements, suitability of comparison groups, and response rate, outcome data, and/or follow-up rate. Mixed methods studies were evaluated using the qualitative scale, the appropriate quantitative scale, and three additional indicators of the strength of mixed methods study design, including relevance of using mixed methods in consideration of the research question, integration of qualitative and quantitative results, and attention to limitations of integration of methods. Due to the controversy surrounding quality appraisal and subsequent exclusion of observational and qualitative studies (Dixon-Woods, et al., 2007; Stroup, et al., 2000), articles were not omitted due to quality. Instead, we used a quality-weighting approach, whereby the results of data synthesis were reported in the context of the quality of the articles and their corresponding findings (Schlosser, Wendt, & Sigafoos, 2007). Specifically, if a finding was extracted from a lower quality study and similar findings were not also reported in higher quality studies, this was highlighted as an indication of reduced confidence in that finding and the need for further research in this area. Findings are reported in the context of the quality ratings in the results section. The individual quality scores are displayed in table 2.1.

### 2.3.4 Data extraction & synthesis

The articles were scanned for findings that identified how family members were negatively affected by having a relative with aphasia post-stroke. For articles published prior to August 10, 2011, relevant findings were extracted from each article by two of the authors (MG and TH or LW) with any discrepancies resolved through discussion. Between August 10, 2011 and September 1, 2013 only the candidate extracted findings following the process described here. Prominent or recurrent family member reports were grouped into categories following a process based on thematic analysis (Dixon-Woods, Agarwal, Jones, Young, & Sutton, 2005). Category names were based on the description in the original study. For example, family members reports of greater involvement in performing household chores, duties, and/or responsibilities were grouped in the category entitled *increased responsibility for household tasks*. In some cases, categories included similar, though not identical family member reports, and the category name was selected to include the subtle differences, such as in the case of the category of *fatigue* and *diminished energy*. Categories were mutually agreed upon through discussion between the authors. The categories were then mapped to the ICF following the ICF linking rules (Cieza, et al., 2005) and synthesized as done in other systematic review that used the ICF as a conceptual framework (McCormack, McLeod, McAllister, & Harrison, 2009; Minis, Heerkens, Engels, Oostendorp, & van Engelen, 2009; Verdonschot, de Witte, Reichrath, Buntinx, & Curfs, 2009). Classification of the results was conducted by the first author (MG) who matched categories generated from the original studies to the categories of the ICF in as much detail as possible (i.e., where sufficient information provided, the mapping went to the third level of ICF classification). Mapping was confirmed through consensus with two of the other authors (TH and LW) only for studies published on or before August 10, 2011.

## 2.4 RESULTS

The search resulted in the retrieval of 31 studies from 10 different countries that met the inclusion criteria. A detailed summary of these studies including the

study aim and study design, quality rating, participant details, outcome measures, and key findings are displayed in table 2.1.

Table 2.1.

*Summary of studies describing negative changes (third-party disability) experienced by family members of people with aphasia.*

| Year<br>Author<br>Country | Study aim<br>Study design<br>Quality rating | FM details<br>Sample size; Response rate; % female; Mean age (range); Relationship to the PWA | PWA details<br>Sample size; Time post-onset; % male;<br>Mean age (range) | FM outcome measures | Key findings –<br>Disability experienced by FMs of PWA |
|---|---|---|---|---|---|
| 2013*<br>Hemsley, Werninck, & Worrall<br>Australia | Aim: To describe adverse events in acute care as experienced by people with aphasia and their spouses.<br>Design: Qualitative, cross-sectional.<br>Quality rating: 75% | n=10; 100% response rate; 80% female; Mean age= 65.3 years (range=57-74); Spouses (100%) | n=10; mean time post-onset=48 months; 80% male; mean age=69.8 years (range=64-82) | In-depth interviews. | FMs experience shock and frustration with unexpected discharge. FMs help PWA to communicate with health professionals and oversee care of PWA. |
| 2012*<br>Howe, et al. | Aim: To identify the goals of FMs of PWA<br>Design: Qualitative, cross- | n=48; 90% response rate; 75% female; mean age=61 (range=24-83); Spouse/partner | n=44; mean time post-onset=57 months; 62% male; mean | Individual semi-structured in-depth interviews. | FMs reported communication and relationship changes between themselves and the PWA, difficulty coping, |

| | | | | | |
|---|---|---|---|---|---|
| Australia | sectional.<br><br>Quality rating: 100% | (64%), sibling (11%), daughter (9%), son (7%), parent (4.5%), other (13.5%) | age=64 years (range=32-83) | | being fatigued, role changes, financial changes, supporting other FMs, and helping the PWA to communicate. |
| 2011*<br><br>Brown, Worrall, Davidson, & Howe<br><br>Australia | Aim: To identify family members' view on living successfully with aphasia<br><br>Design: Qualitative, cross-sectional<br><br>Quality rating: 100% | n=24; 92% response rate; 62.5% female; mean age=62 (range=40-87); Spouse (79%), parent (12.5%), brother (4%), daughter (4%) | n=23; time post-onset not stated; 52% male; mean age=62.5% (range=40-86) | Semi-structured in-depth interviews. | FMs helped the PWA, in communication, companionship, and domestic activities, as well as helping other FMs. FMs had less time for social activities and experienced negative emotions. |
| 2011*<br><br>McGurk, Kneebone, & Pit ten Cate<br><br>UK | Aim: To explore the association between depression and coping in FMs of PWA.<br><br>Design: Quantitative, cross-sectional.<br><br>Quality rating: 100% | n=153; 90% response rate; 81% female; age 15% under 50 years, 59% 50-69 years, 25% ≥70 years; Spouse/partner (85%), Child (11%) | n=153; 32% 1 year post onset, 11% ≥10 years post-onset; 69% male; age 7% <49 years, 64% 60-79 years, | The Centre for Epidemiologic Studies Depression Scale (CES-D) | 46% of FMs scored above the cut-off for depression. |
| 2010<br><br>Gillespie, Murphy, & Place<br><br>UK | Aim: To identify divergent perspectives of PWA and their FMs.<br><br>Design: Mixed methods,<br><br>Cross-sectional.<br><br>Quality rating: 50% | n=20; Response rate not stated; 65% female; Mean age not stated; Spouses (80%), Parents (10%), daughters (10%) | n=20; mean time post-onset=30 months; 55% male; Mean age=59 years | Interpersonal Perception Method; Communication analysis | FMs helped PWA to communicate, perform household tasks on PWA's behalf, and encourage PWA's independence. FMs tried to protect PWA by hiding the burden of care. |

| | | | | | |
|---|---|---|---|---|---|
| 2010<br><br>Hallé, Duhamel, & Le Dorze<br><br>Canada | Aim: To explore the change in relationship between daughters and their mothers with aphasia, from the daughter's perspective.<br><br>Design: Qualitative, Longitudinal.<br><br>Quality rating: 100% | n=4; Response rate not stated; 100% female; Age range=37-56 years;<br><br>Daughters (100%) | n=3; 2-5 months post-onset, 4-10 months post-onset, 10-15 months post-onset; 100% female; Age (range=67-78 years) | Semi-structured interviews | FMs provided communication and caregiving support to the PWA and experience negative emotions associated with these tasks. |
| 2010<br><br>Le Dorze & Signori<br><br>Canada | Aim: To identify the needs and barriers of spouses of PWA.<br><br>Design: Qualitative, Cross-sectional.<br><br>Quality rating: 100% | n=11; 61% response rate; 82% female; Mean age=60.5years (range=51-68); Spouses (100%) | n=11, 3-15 years post-onset; 82% male; Mean age=63.5years (range=51-76) | Group Interview | FMs described caregiving responsibilities (e.g., assisting PWA with communication, healthcare) and changes in FMs own relationships and activities. |
| 2010<br><br>Paul & Sanders<br><br>USA | Aim: To explore the education of FMs within the healthcare system.<br><br>Design: Qualitative, Cross-sectional.<br><br>Quality rating: 75% | n=9, response rate not stated; 78% female; Mean age=58 years (range=44-78); Spouse (44%), Daughter (22%), Son (11%), Friend/significant other (22%) | n=9; <2 years post-onset; 67% male; Mean age=71 years (range=51-84) | In-depth interviews | FMs experienced negative emotions and changes to their communication with the PWA. FMs also reported helping PWA communicate with others (e.g., for finances, insurance, and health). |
| 2010<br><br>Pringle, Hendry, | Aim: To understand the experience of returning home after stroke, from the perspective | n=4, response rate not stated; % female not stated; Age not stated; | n=4; 1 month post-onset; % male not stated; | In-depth interviews; self-report diaries | FMs recorded emotional changes, changes in the relationship with PWA, and developing new ways to |

| | | | | | |
|---|---|---|---|---|---|
| McLafferty, & Drummond<br><br>UK | of PWA and their FMs.<br><br>Design: Qualitative, Longitudinal.<br><br>Quality rating: 50% | Relationship to PWA not stated | Age not stated | | communicate. |
| 2009<br><br>Le Dorze, Tremblay & Croteau<br><br>Canada | Aim: To describe an adult daughter's adaptation to her father's aphasia.<br><br>Design: Qualitative, Longitudinal<br><br>Quality rating: 100% | n=1; Response rate not applicable; 100% female; 31 years; Daughter (100%) | n=1; During the first year post-stroke (before and after outpatient rehabilitation and 3 months later); 100% male; 60 years | Semi-structured, in depth, face-to-face interview | The daughter's sources of stress and relationship with her father changed over time. |
| 2009<br><br>Nätterlund<br><br>Sweden | Aim: To investigate close relatives' perceptions of the influence of aphasia on their own life.<br><br>Design: Qualitative,<br><br>Cross-sectional<br><br>Quality rating: 50% | n=14; 70% response rate; 50% female; Age not stated; Spouse (50%), parent (29%), sibling (7%), child (7%), friend (7%) | n=14; 2-11 years post-onset; 64% male; Mean age=55.6 years (range=28-70) | Interviews | FMs identified life changes that occurred post-aphasia, such as loss of friends, emotional changes, and role changes. |
| 2008<br><br>Barrow<br><br>Ireland | Aim: To identify how narratives of disability help a PWA make sense of the stroke and aphasia.<br><br>Design: Qualitative,<br><br>Cross-sectional | n=2; Response rate not applicable; 0% female; Ages not specifically stated, participants were 14 and <40 years; Son (50%), | n=1; 2 years post-onset; 0% male; mid-40's | In-depth interviews; Participant observation; Artefact collection | FMs experienced role changes and sadness/confusion. |

| | | | | | |
|---|---|---|---|---|---|
| | Quality rating: 100% | brother (50%) | | | |
| 2006<br><br>Bakas, Kroenke, Plue, Perkins, & Williams<br><br>USA | Aim: To compare the outcomes for caregivers of people with and without aphasia post-stroke.<br><br>Design: Quantitative, Longitudinal, Comparison<br><br>Quality rating: 100% | n=46; Response rate not stated; 91% female; Mean age=52 years (range=21-76);<br><br>Spouse (43.5%), adult child (41.3%), other (15.2%) | n=46; 1 month, 4 months post-onset;<br><br>56% male; Mean age=64.2 years (range=38-85) | Oberst Caregiving Burden Scale; Patient Health Questionnaire,<br><br>Depression Scale; Bakas Caregiving Outcomes Scale; Revised Memory and Behaviour Problem Checklist | FMs of PWA experienced reduced time for social and family activities, diminished level of energy, as well as difficulty communicating with the PWA, managing difficult behaviours, and managing finances. |
| 2003<br><br>Michallet, Tétreault, & Le Dorze<br><br>Canada | Aim: To determine the consequences of severe aphasia on the spouses of PWA<br><br>Design: Qualitative, Cross-sectional<br><br>Quality rating: 100% | n=5; Response rate not stated; 80% female; Mean age=66 years (range=59-71); Spouses (100%) | n=5; post-onset time not stated; 80% male; Mean age=69 years (range=64-77) | Qualitative interviews | Spouses experienced stress related to changes in their communication with the PWA and others, interpersonal relationships, home/administrative responsibilities, leisure activities, and finances. |
| 2001<br><br>Lemieux, Cohen-Schneider, & Holzapfel | Aim: To investigate how sexuality changed for couples post-onset of aphasia.<br><br>Design: Qualitative, | n=6; 25% response rate; 83% female;<br><br>Age not stated;<br><br>Spouse (100%) | n=6; 1-3 years post-onset; 83% male;<br><br>65 years (range=53-70) | Joint structured questionnaire with PWA<br><br>35-item written questionnaire | Aphasia affected sexual relationship between PWA and their spouse. |

| | | | | | |
|---|---|---|---|---|---|
| Canada | Cross-sectional<br><br>Quality rating: 25% | | | | |
| 2001<br><br>Michallet, Le Dorze, & Tétreault<br><br>Canada | Aim: To describe the needs of the spouse of the person with severe aphasia.<br><br>Design: Qualitative,<br><br>Cross-sectional<br><br>Quality rating: 75% | n=6; Response rate not stated; 83% female; Mean age=66 years (range=59-71); Spouse (100%) | n=6; Post-onset time not stated; 83% male; Mean age=69 years (range=64-77) | Semi-structured interviews | Spouses identified changes in communication with PWA, interpersonal relationships, social networks, level of stress and energy. |
| 1999<br><br>Santos, Farrajota, Castro-Caldas, & De Sousa<br><br>Portugal | Aim: To investigate the opinions of spouses of PWA compared to controls.<br><br>Design: Quantitative,<br><br>Cross-sectional,<br><br>Comparison<br><br>Quality rating: 100% | n=55; 69% response rate; 55% female; Mean age=57 years (range=47-67); Spouse (100%) | n=55; 1-11 years post-onset; 31% male; Age not stated | European Brain Injury Questionnaire | Spouses of PWA demonstrated changes in their cognition, motivation, depression, and communication. |
| 1999<br><br>Zemva<br><br>Slovenia | Aim: To understand the wishes and expectations of PWA and their FMs.<br><br>Design: Qualitative,<br><br>Cross-sectional<br><br>Quality criteria: 25% | n=20; Response rate not stated; 85% female; Mean age=68 years (range=34-87);<br><br>Wife (60%), husband(5%), son(10%), | n=20; 1-48 months post-onset; 75% male;<br><br>Mean age=68 years (range=57-82) | Structured interview | FMs reported changes to communication, and concerns due to aphasia-related changes, changes to social life, changes to marital life. |

| | | | | | |
|---|---|---|---|---|---|
| | | daughter(25%) | | | |
| 1998<br><br>Denman<br><br>UK | Aim: To describe the needs of spouses of PWA and their suggested solutions.<br><br>Design: Qualitative,<br><br>Cross-sectional<br><br>Quality rating: 50% | n=9; 60% response rate; Gender not stated; Age not stated;<br><br>Spouses(100%) | n=9; >12 months post-onset; Gender not stated; Age not stated | Semi-structured Interview | Spouses experienced role changes, and need support, information, training, and respite. |
| 1996<br><br>Hemsley & Code<br><br>Australia | Aim: To examine factors contributing to the recovery of PWA.<br><br>Design: Quantitative, Longitudinal, Descriptive case series<br><br>Quality rating: 75% | n=5; Response rate not stated; 80% female; Age not stated; Spouse (80%), daughter-in-law (20%) | n=5; 3 months and 9 months post-onset; 60% male; Mean age=not stated<br><br>(range=63-70) | General Health Questionnaire; Code-Muller Protocols | Psychosocial well being of FMs decreased over time and was poorer than the PWA in some areas. |
| 1995<br><br>Herrmann, Britz, Bartels, & Wallesch<br><br>Germany | Aim: To describe the determining factors of coping for people with stroke with and without aphasia and their FMs.<br><br>Design: Quantitative, Longitudinal, Comparison<br><br>Quality rating: 100% | n=25(initial), n=12(final); Response rate not stated; Gender not stated;<br><br>Age not stated; Relationship to PWA not stated | n=25(initial), n=12(final); 1 week, 1 month, 6 months, 1 year post-onset; 56-58% male;<br><br>Mean age=64 years (range=21-75) | Freiburg Questionnaire on Coping with Illness, short version; Illness-related causal attributions and control beliefs; The severity of psychosocial changes; Code-Muller Protocols | FMs of PWA experienced changes to their job, work, household, and social lives. |

| | | | | | |
|---|---|---|---|---|---|
| 1995<br><br>King & Shade-Zeldow<br><br>USA | Aim: To compare the process of adapting to a partner's stroke with and without aphasia.<br><br>Design: Mixed methods, Longitudinal, Comparison<br><br>Quality rating: 50% | n=15; 61% response rate; 67% female; Mean age not stated, but 60% were over 56 years; Spouse (100%) | n=20; Prior to rehabilitation discharge, 6-weeks, 10-weeks, and 1-year post-discharge; Gender not stated; Age not stated | The Center for Epidemiologic Studies – Depression; Open-ended interview guide | Spouses of PWA experienced a high level of depression and difficulty with role changes. |
| 1995<br><br>Le Dorze & Brassard<br><br>Canada | Aim: To describe and understand the meaning and experience of the consequences of aphasia for relatives and PWA.<br><br>Design: Qualitative,<br><br>Cross-sectional<br><br>Quality rating: 75% | n=9; Response rate not stated; 67% female; Mean age=52 years (range=20-70);<br><br>Spouse (44%), friend (11%), cousin (11%), niece (11%), mother (11%), daughter (11%) | n=9; 2-14 years post-onset; 56% male<br><br>Mean age=54 years, (range 41-69) | Semi-structured qualitative research interviews | FMs experienced handicaps in communication, interpersonal relationships, responsibilities, work and leisure activities. |
| 1995<br><br>Salonen<br><br>Finland | Aim: To determine the physical, functional, and social changes post-stroke and coping for PWA and FMs.<br><br>Design: Quantitative, Cross-sectional | n=164; 60% response rate; Gender not stated; Age not stated;<br><br>Spouse (74%), child (20%), another relative | n=164; 3-4 years post-onset; 44% male;<br><br>Mean age=65 years (range not stated) | The Life Situation Questionnaire | FMs reported changes to their job, social, and leisure time. |

| | | | | | |
|---|---|---|---|---|---|
| | Quality rating: 50% | (5%) | | | |
| 1993<br><br>Williams<br><br>USA | Aim: To measure the impact of aphasia on marital satisfaction<br><br>Design: Quantitative, Cross-sectional/ retrospective<br><br>Quality rating: 75% | n=40; Response rate not stated; 83% female; Age not stated; Spouse (100%) | n=40; 1 month - 30 years post-onset; 83% male; Mean age=68 years (range=44-75) | Marital Satisfaction Scale; Marital Comparison Level Index | FMs experienced a lower level of marital satisfaction post-onset of aphasia compared to before the onset of aphasia. |
| 1989<br><br>Christensen & Anderson<br><br>USA | Aim: To examine the impact of stroke with and without aphasia on spouse's role changes, emotional problems, social adjustment, and partner's communication abilities.<br><br>Design: Quantitative, Cross-sectional<br><br>Comparison<br><br>Quality rating: 50% | n=11; 49% response rate; 90% female; Mean age= 63 years<br><br>(range not stated);<br><br>Spouse (100%) | n=11; 1-1.5 years post-onset; 90% male; Age not stated | Researcher-developed questionnaire to examine role change, emotional problems, and social adjustment | Spouses of PWA experienced roles changes, feelings of loss of control, anxiety, and irritation. They also reported assisting the PWA with personal care, medical care, and finances. |
| 1988<br><br>Ross & Morris<br><br>UK | Aim: To explore the extent to which aphasia related changes contribute to psychological problems of spouses of PWA.<br><br>Design: Quantitative,<br><br>Cross-sectional<br><br>Quality rating: 75% | n=20; Response rate not stated; 60% female; Mean age=66 years (range=53-82); Spouse (100%) | n=20; 4-108 months post-onset; 60% male;<br><br>Mean age=68 years (range=53-78) | Modified Arts & Hoops Questionnaire; Strain Scale; Beck Depression Inventory;<br><br>General Health Questionnaire | Spouses of PWA demonstrated psychiatric morbidity and strain, but not increased depression. |

| | | | | | |
|---|---|---|---|---|---|
| 1986<br><br>Wade, Hewed, David, & Enderby<br><br>UK | Aim: To examine the natural history of aphasia including frequency, prognosis, other stroke-induced disability, and other outcomes.<br><br>Design: Quantitative,<br><br>Longitudinal, Comparison<br><br>Quality rating: 100% | n=30; Response rate not stated; Gender not stated; Age not stated;<br><br>Carer (100%), specific relationship not stated | n (1 week)=545 (56%), n (2-4 weeks)=568 (91%),<br><br>n (6-7 months)=470 (96%); Age not stated; Gender not stated | Wakefield Depression Inventory; General Health Questionnaire (GHQ) | Carers of PWA experienced depression. |
| 1979<br><br>Kinsella & Duffy<br><br>UK | Aim: To investigate the readjustment of spouses of people post-stroke with and without aphasia and to determine the particular problems of spouses of PWA. Design: Quantitative,<br><br>Cross-sectional, Comparison<br><br>Quality rating: 75% | n=79; Response rate not stated; 70% female; Mean age=60 years (range=55-74); Spouse (100%) | n=79 (8 aphasia only, 28 aphasia and hemiplegia, 43 hemiplegia only);<br><br>3 months -3 years post-onset; 70% male; All <80 years | General Health Questionnaire; Wakefield Depression Inventory; The Social Adjustment Scale | Spouses of PWA reported poor social adjustment and marital problems. |
| 1976<br><br>Artes & Hoops<br><br>USA | Aim: To examine the effects upon family life when a husband has a stroke, comparing those with and without aphasia.<br><br>Design: Quantitative, Cross-sectional, Comparison<br><br>Quality rating: 50% | n=35; 100% response rate; 100% female; Mean age=55 years (range=25-82); Wife (100%) | n=35; 3 to >36 months post-onset; 100% male; Mean age=58 years (range not stated) | Researcher-designed interview based questionnaire | Wives of PWA reported psychological and emotional difficulties. |

| | | | | | |
|---|---|---|---|---|---|
| 1970<br><br>Malone, Ptacek, & Malone<br><br>USA | Aim: To measure the frequency and intensity of attitudes of spouses of PWA.<br><br>Design: Quantitative,<br><br>Cross-sectional<br><br>Quality rating: 0% | n=30; Response rate not stated; 67% female; Mean age=48 years (range=24-63;<br><br>Spouse (100%) | n=30; 6 months to 3 years post-onset; Gender not stated; Age not stated | Questionnaire designed by researchers;<br><br>Index of Status Characteristics | All spouses reported guilt, unrealistic attitudes, and overprotection, most (90%) reported social withdrawal. |

FM=family member, PWA=person with aphasia

* Papers added when this review was updated with publications retrieved between August 11, 2011 and September 1, 2013.

### 2.4.1 Study aim

Of the 31 included studies, 14 specifically aimed to describe how aphasia affects family members. The purpose of the remaining studies varied. An additional seven investigated recovery, adaptation, and/or coping of family members and/or people with aphasia. Eight studies looked at wishes, expectations, needs, attitudes, or opinions of family members of people with aphasia. Two studies were more specific in their research aims, investigating the effect of aphasia on marital satisfaction and the changes to the sexual relationship between spouses following aphasia. In 11 of the 31 included studies, the person with aphasia was the focus, though family members were also included. Despite the wide variety of study aims, all those included in the review provided examples of how family members are negatively affected by having a relative with aphasia.

### 2.4.2 Study design

Sixteen qualitative, thirteen quantitative, and two mixed methods study were identified. Eight were comparison studies. Seven of those compared the effects of aphasia on family members versus stroke alone, and one compared spouses of people with aphasia with a normal control group. Eight of the studies were longitudinal and followed participants over a 1- to 11-month time frame, with the remaining studies being cross-sectional in nature.

### 2.4.3 Participant details

The participant characteristics also varied considerably between studies. The family members from 14 studies were exclusively spouses, while 14 included and/or focused only on other relations such as children, siblings, friends, and/or other relatives. Three studies did not state the relationship between the participants. Family member participants ranged in age from 14 to 87 years. Participants with aphasia were 21 to 85 years and ranged from 1-month to 30-years post-onset of aphasia due to stroke. Most family members were female, with the majority of people with aphasia

being male. Sample sizes ranged from one to 164 for family members and one to 568 for people with aphasia and were judged to be appropriate for the selected methodology.

### 2.4.4 Family member outcome measures

Across the studies, twenty-four different quantitative outcome measures were used to investigate physical, psychological, and social changes experienced by family members. The most commonly used measures were the General Health Questionnaire, researcher-designed questionnaires, and the Wakefield Depression Inventory. Qualitative interviews (e.g., semi-structured, in-depth, group interviews, etc.) were used in all the qualitative studies as the main source of data collection, with one study also including participant observation and another self-report diaries.

### 2.4.5 Data synthesis through mapping to the ICF

The synthesis of the study findings and subsequent mapping of the findings to the ICF revealed effects on family members in the Body Functions component, as well as the Activities and Participation component. Details of the data synthesis and ICF mapping including the ICF category, ICF code, and corresponding family member report can be found in table 2.2 for Body Functions and Structures and table 2.3 for Activities and Participation.

Within the Body Functions component, findings were mapped only to the mental functions chapter. In the Activities and Participation component, findings were mapped to seven of the nine chapters, including a) General tasks and demands, b) Communication, c) Self-care, d) Domestic life, e) Interpersonal interactions and relationships, f) Major life areas, and, g) Community, social, and civic life.

Table 2.2.

*Synthesis of the negative study findings mapped to the Body Functions and Structures component of the ICF: Third-party disability in aphasia according to the existing literature.*

| ICF Chapter | ICF Category | ICF Code | ICF Code Name | Corresponding effect on family member | References |
|---|---|---|---|---|---|
| Mental Functions | b126 Temperament and personality functions | b1263 | Psychic stability | Altered mood | Santos, Farrajota, Castro-Caldas, & De Sousa (1999) |
| | | b1265 | Optimism | Decreased optimism | Bakas, Kroenke, Plue, Perkins, & Williams (2006) |
| | | b1266 | Confidence | Decreased self-esteem, insecurity | Bakas, Kroenke, Plue, Perkins, & Williams (2006); Gillespie, Murphy, & Place (2010) |
| | | | | Loss of control over the situation | Christensen & Anderson (1989) |
| | b130 Energy and drive functions | b1300 | Energy Level | Fatigue & Diminished Energy | Bakas, Kroenke, Plue, Perkins, & Williams (2006); Howe, et al., (2012); Le Dorze & Brassard (1995); Michallet, Tétreault, & Le Dorze (2003); Michallet, Le Dorze, & Tétreault (2001) |
| | b134 Sleep functions | b1342 | Maintenance of sleep | Change of sleeping habits | Artes & Hoops (1976) |

| | | | | | |
|---|---|---|---|---|---|
| | b152 Emotional functions | b1522 | Range of emotion | Anxiety | Christensen & Anderson (1989); Hemsley & Code (1996); Le Dorze, Tremblay, & Croteau (2009); Nätterlund (2010) |
| | | | | Worry | Artes & Hoops (1976); Brown, Worrall, Davidson, & Howe (2011); Gillespie, Murphy, & Place (2010); Hallé, Duhamel & Le Dorze (2010); Le Dorze & Brassard (1995); Le Dorze, Tremblay, & Croteau (2009), Michallet, Tétreault, & Le Dorze (2003); Nätterlund (2010); Paul & Sanders (2010); Pringle, Hendry, McLafferty & Drummond (2010); Zemva (1999) |
| | | | | Irritation | Christensen & Anderson (1989) |
| | | | | Frustration | Brown, Worrall, Davidson, & Howe (2011); Hallé, Duhamel & Le Dorze (2010); Hemsley & Code (1996); Le Dorze, Tremblay, & Croteau (2009); Paul & Sanders (2010); Pringle, Hendry, McLafferty & Drummond (2010) |
| | | | | Guilt | Hallé, Duhamel & Le Dorze (2010); Malone, Ptacek, & Malone (1970) |
| | | | | Feeling of obligation and burden | Hallé, Duhamel & Le Dorze (2010); Le Dorze & Signori (2010) |
| | | | | Shock | Paul & Sanders (2010); Hemsley , Werninck, & Worrall (2013) |
| | | | | Strain | Ross & Morris (1988) |
| | | | | Stress | Gillespie, Murphy, & Place (2010); Le Dorze, Tremblay, & Croteau (2009); Michallet, Le Dorze, & Tétreault (2001); Paul & Sanders (2010) |

| | | |
|---|---|---|
| | Sadness | Barrow (2008); Hallé, Duhamel & Le Dorze (2010); Le Dorze, Tremblay, & Croteau (2009) |
| | Confusion | Barrow (2008) |
| | Loneliness | Kinsella & Duffy (1979) |
| | Boredom | Kinsella & Duffy (1979) |
| | Uneasiness | Le Dorze & Brassard (1995) |
| | Emotional changes | Bakas, Kroenke, Plue, Perkins, & Williams (2006) |
| | Maintaining emotional balance | King & Shade-Zeldow (1995) |
| | Fear | Le Dorze, Tremblay, & Croteau (2009); Paul & Sanders (2010) |

Table 2.3.

*Synthesis of the study findings mapped to the Activities and Participation component of the ICF: Third-party disability in aphasia according to the existing literature.*

| ICF Chapter | ICF Category | ICF Code | ICF Code Name | Corresponding family member report | References |
|---|---|---|---|---|---|
| General tasks and demands | d240 Handling stress and other psychological demands | d2401 | Handling stress | Difficulty coping with stress | Bakas, Kroenke, Plue, Perkins, & Williams (2006); Howe, et al., (2012); Pringle, Hendry, McLafferty & Drummond (2010) |
| Communication | d350 Conversation | d3503 | Conversing with one person | Difficulty communicating with the PWA | Bakas, Kroenke, Plue, Perkins, & Williams (2006); Brown, Worrall, Davidson, & Howe (2011); Hallé, Duhamel & Le Dorze (2010); Howe, et al., (2012); Kinsella & Duffy (1979); Le Dorze, Tremblay, & Croteau (2009); Michallet, Le Dorze, & Tétreault (2001); Michallet, Tétreault, & Le Dorze (2003); Paul & Sanders (2010); Williams (1993) |
| | | d3550 | Discussion with one person | Less discussion with PWA about decisions | Gillespie, Murphy, & Place (2010) |
| Self-care | d550 Eating | d550 | Eating | Change to eating habits | Artes & Hoops (1976) |
| | d570 Looking after | d5702 | Maintaining one's health | Difficulty maintaining one's | Artes & Hoops (1976); King & Shade-Zeldow (1995) |

| | | | | | |
|---|---|---|---|---|---|
| | one's health | | | own health | |
| Domestic life | d620 Acquisition of goods and services | d6200 | Shopping | Increased shopping | Hemsley & Code (1996) |
| | d630 Preparing meals | d6300 | Preparing simple meals | Increased responsibility for cooking | Denman (1998); Hemsley & Code (1996); King & Shade-Zeldow (1995); Nätterlund (2010) |
| | d640 Doing housework | | | Increased responsibility for household tasks | Bakas, Kroenke, Plue, Perkins, & Williams (2006); Brown, Worrall, Davidson, & Howe (2011); Denman (1998); Herrmann, Britz, Bartels, & Wallesch (1995); Michallet, Le Dorze, & Tétreault (2001); Nätterlund (2010) |
| | | | | Increased responsibility for cleaning | Hemsley & Code (1996) |
| | | d6400 | Washing and drying clothes and garments | Increased responsibility for laundry | King & Shade-Zeldow (1995) |
| | d660 Assisting others | d6609 | | Providing care to the PWA | Bakas, Kroenke, Plue, Perkins, & Williams (2006); Brown, Worrall, Davidson, & Howe (2011); Denman (1998); Gillespie, Murphy, & Place (2010); Hallé, Duhamel & Le Dorze (2010); Hemsley, Werninck, & Worrall (2013); Herrmann, Britz, Bartels, & Wallesch (1995); Howe, et al., (2012); Le Dorze & Brassard (1995); Le Dorze & Signori (2010); Le Dorze, Tremblay, & Croteau (2009); Malone, Ptacek, & Malone (1970); Michallet, Le Dorze, & Tétreault |

| | | | | | |
|---|---|---|---|---|---|
| | | | | | (2001); Paul & Sanders (2010); Pringle, Hendry, McLafferty & Drummond (2010); Salonen (1999) |
| | | | | Providing care to others | Brown, Worrall, Davidson, & Howe (2011) |
| | | d6600 | Assisting others with self-care | Assisting PWA with personal care | Christensen & Anderson (1989); Hallé, Duhamel & Le Dorze (2010); Nätterlund (2010) |
| | | d6601 | Assisting others in movement | Assisting PWA with mobility | Bakas, Kroenke, Plue, Perkins, & Williams (2006) |
| | | | | Taking PWA to appointments | Howe, et al., (2012) |
| | | d6602 | Assisting others in communication | Assisting PWA to communicate | Brown, Worrall, Davidson, & Howe (2011); Gillespie, Murphy, & Place (2010); Hallé, Duhamel & Le Dorze (2010); Hemsley , Werninck, & Worrall (2013); Howe, et al., (2012); Le Dorze & Brassard (1995); Le Dorze & Signori (2010); Michallet, Tétreault, & Le Dorze (2003); Michallet, Le Dorze, & Tétreault (2001); Nätterlund (2010); Paul & Sanders (2010) |
| | | d6604 | Assisting others in nutrition | Preparing food for PWA | Le Dorze & Signori (2010); Nätterlund (2010) |
| | | d6605 | Assisting others in health maintenance | Medical and health care assistance | Barrow (2008); Christensen & Anderson (1989); Hallé, Duhamel, & Le Dorze (2010); Hemsley , Werninck, & Worrall (2013); King & Shade-Zeldow (1995); Le Dorze & Signori (2010); Paul & Sanders (2010) |
| Interpersonal | d750 Informal | d7500 | Informal | Change in | Bakas, Kroenke, Plue, Perkins, & Williams (2006); Michallet, |

| | | | | | |
|---|---|---|---|---|---|
| interactions and domestic relationships | social relationships | | relationships with friends | relationship with friends | Tétreault, & Le Dorze (2003) |
| | | | | Less time for friends | Bakas, Kroenke, Plue, Perkins, & Williams (2006); Hemsley & Code (1996); Malone, Ptacek, & Malone (1970); Salonen (1995); Zemva (1999) |
| | | | | Loss of friends | Denman (1998); Le Dorze & Brassard (1995); Michallet, Le Dorze, & Tétreault (2001); Nätterlund (2010) |
| | d760 Family relationships | | | Less time for family | Bakas, Kroenke, Plue, Perkins, & Williams (2006) |
| | | | | Changes to family relationships | Gillespie, Murphy, & Place (2010); Le Dorze & Signori (2010); Michallet, Tétreault, & Le Dorze (2003); Pringle, Hendry, McLafferty & Drummond (2010) |
| | | d7600 | Parent-child relationships | Relationship changes between child and parent | Gillespie, Murphy, & Place (2010); Hallé, Duhamel & Le Dorze (2010); Kinsella & Duffy (1979); Le Dorze & Signori (2010); Le Dorze, Tremblay, & Croteau (2009); Michallet, Tétreault, & Le Dorze (2003) |
| | d770 Intimate relationships | d7701 | Spousal relationships | Reduced marital satisfaction | Williams (1993) |
| | | | | Change to marriage relationship | Brown, Worrall, Davidson, & Howe (2011); Kinsella & Duffy (1979); Le Dorze & Signori (2010); Howe, et al., (2012); Michallet, Le Dorze, & Tétreault (2001); Michallet, Tétreault, & Le Dorze (2003); Williams (1993); Zemva (1999) |
| | | d7702 | Sexual relationships | Decreased sexual activity | Artes & Hoops (1976); Kinsella & Duffy (1979); Lemieux, Cohen-Schneider, Holzapfel (2001); Le Dorze & Brassard |

| | | | | | |
|---|---|---|---|---|---|
| | | | | | (1995); Williams (1993) |
| | | | | Decreased sexual desire and physical attractiveness | Lemieux, Cohen-Schneider, Holzapfel (2001); Williams (1993) |
| Major life areas | d850 Remunerative employment | d8502 | Full-time employment | Gave up job | Hemsley & Code (1996); Salonen (1995) |
| | | | | Moving from full to part-time employment | Salonen (1995) |
| | d855 Non-remunerative employment | | | Gave up volunteer position | Denman (1998) |
| | d830 Higher education | | | Dropped a course | Le Dorze & Brassard (1995) |
| | d870 Economic self-sufficiency | d8700 | Personal economic resources | Increased role in managing finances | Artes & Hoops (1976); Bakas, Kroenke, Plue, Perkins, & Williams (2006); Barrow (2008); Christensen & Anderson (1989); Denman (1998); Gillespie, Murphy, & Place (2010); Hallé, Duhamel, & Le Dorze (2010); Howe, et al., (2012); King & Shade-Zeldow (1995); Le Dorze & Brassard (1995); Michallet, Le Dorze, & Tétreault (2001); Michallet, Tétreault, & Le Dorze (2003); Paul & Sanders (2010) |
| | | | | Financial burden | Howe, et al., (2012) |
| Community, social and civic life | d910 Community life | d9100 | Informal associations | Less time for social activities | Artes & Hoops (1976); Bakas, Kroenke, Plue, Perkins, & Williams (2006); Brown, Worrall, Davidson, & Howe (2011); Hemsley & Code (1996); Herrmann, Britz, Bartels, & Wallesch (1995); Kinsella & Duffy (1979); Le Dorze & Signori (2010); Malone, Ptacek, & Malone (1970); Michallet, |

| | | | | | |
|---|---|---|---|---|---|
| | | | | | Tétreault, & Le Dorze (2003); Salonen (1995) |
| | d920 Recreation and leisure | | | Change in recreational/leisure time activities | Herrmann, Britz, Bartels, & Wallesch (1995); Kinsella & Duffy (1979); Le Dorze & Brassard (1995); Le Dorze & Signori (2010); Le Dorze, Tremblay, & Croteau (2009); Pringle, Hendry, McLafferty & Drummond (2010); Salonen (1995); Zemva (1999) |
| | | | | Decrease in number of holidays | Herrmann, Britz, Bartels, & Wallesch (1995); Le Dorze & Brassard (1995); Malone, Ptacek, & Malone (1970) |
| | | d9205 | Socializing | Poorer social functioning | Artes & Hoops (1976); Hemsley & Code (1996) |
| | | | | Withdrawal from social situations | Malone, Ptacek, & Malone (1970) |

PWA=Person with aphasia.

### 2.4.6 Quality ratings

Quality rating scores ranged from 0 to 100%. The selected methodology was generally appropriate for the stated aim of the research, however, most samples were based on convenience with few measures in place for the minimization of selection bias and assurance that the sample was representative of the population under study. Many of the qualitative studies did not address the principle of reflexivity and several did not adequately relate the findings to the context. Some quantitative studies provided a poor description and/or justification of the measurement tool used. Participant response rates varied from 25 to 100%, though this was poorly reported with only 44.8% of studies including this information.

Many family member reports were only supported by one or two studies of low quality [e.g., loss of control over the situation (Christensen & Anderson, 1989), change of sleeping habits (Artes & Hoops, 1976), irritation (Christensen & Anderson, 1989), strain (Ross & Morris, 1988), maintaining emotional balance (King & Shade-Zeldow, 1995), less discussion with the person with aphasia (Gillespie, Murphy, & Place, 2010), changes to eating habits (Artes & Hoops, 1976; King & Shade-Zeldow, 1995), moving from full to part-time employment (Salonen, 1995), gave up volunteering (Denman, 1998), withdrawal from social situations (Malone, Ptacek, & Malone, 1970)]. Thus, there is reduced confidence in these examples of how aphasia can negatively impact family members. However, any finding that was only supported by one study should be considered with less confidence, especially considering the small sample size of many of the studies.

### 2.4.7 Findings that could not be mapped to the ICF

Some findings were too ambiguous to be categorized by the ICF so they could not be coded. For example, Artes and Hoops (1976) and Le Dorze and Brassard (1995) identified that the health of family members of people with aphasia was affected, while Santos, Farrajota, Castro-Caldas, and De Sousa (1999) identified consequent problems and life changes, and Williams (1993) identified lifestyle changes in spouses of people with aphasia. Without further detail, it was not possible to link “health”, “consequent life problems”, or “lifestyle changes” to the ICF. Bakas,

Kroenke, Plue, Perkins, and Williams (2006) identified unspecified physical health changes in caregivers of people with aphasia and diminished physical functioning. It is unclear based on their description whether this would fit in the ICF Activity and Participation chapter on mobility. These reports are given the code "nd", not definable (Cieza, et al., 2005).

## 2.5 DISCUSSION

The purpose of this review was to use the framework of the ICF to synthesize the research that reported on the negative effects of aphasia on family members in order to provide a description of our current understanding of third-party disability in aphasia. The results show that having a relative with aphasia has negative effects on many areas of the family member's functioning, though findings are not conclusive. Specific areas for further investigation have been identified and will be discussed below.

### 2.5.1 Health conditions and impairments

The results reveal that family members of people with aphasia experience changes to their mental functions in the Body Functions domain of the ICF, specifically within the categories of temperament and personality, energy and drive functions, sleep functions, and emotional functions. Negative emotions, such as irritation, frustration, and sadness, were retrieved and categorized; however, the presence of depression and minor psychiatric disorders was also specifically measured in some of the studies (e.g., McGurk, et al., 2011; Howe, et al., 2012). These disorders are not classified by the ICF; they are health conditions that are classified according to the *International Statistical Classification of Diseases and Related Health Problems, 10th Revision* (ICD-10) under chapter 5, mental and behavioural disorders (WHO, 1990). The issue of whether aphasia is associated with the development of depression or minor psychiatric disorders in family members of people with aphasia is relevant to the research question.

Though several studies have shown that family members of people with aphasia develop psychiatric morbidity according to the General Health Questionnaire (Hemsley & Code, 1996; Kinsella & Duffy, 1978; Ross & Morris, 1988), the presence

and progression of depression is not well explained by the current literature. Some studies have shown that family members of people with aphasia have a high rate of depression (Bakas, et al., 2006; Hemsley & Code, 1996; King & Shade-Zeldow, 1995; Kinsella & Duffy, 1978; McGurk, et al., 2011; Wade, Hewer, David, & Enderby, 1986), while others do not (Ross & Morris, 1988). The difference may be explained by the use of anti-depressants, which is infrequently reported in the literature and may result in an underestimate of the presence of depressive symptoms (Bakas, et al., 2006). For example, Bakas and colleagues (2006) found that 18.1% of family members of people with stroke, with or without aphasia, scored in the moderately depressed range, but noted that an additional 18.1% of family members were taking antidepressant medications. Kinsella and Duffy (1978) reported that 78% of family members in their study took medication for nervous disorders, though the use of anti-depressants was not specifically stated. Another variable that should be considered is the degree of communication difficulty, as family members of people with more severe aphasia may experience a greater number of depressive symptoms (McGurk, et al., 2011).

Even when depression is identified, the evolution of the depressive symptoms is not agreed upon. King and Shade-Zeldow (1995) found that family members of people with aphasia experienced depression that improved over the first year post-stroke but, Bakas and colleagues (2006) reported that depressive symptoms of family members of people with aphasia did not improve between one and four months post-stroke and the family member who experienced depression in Hemsley and Code's (1996) study became depressed between three and nine months post-stroke. Further research in this area is needed to determine the prevalence and time course of depression in family members of people with aphasia (McGurk, et al., 2011).

### 2.5.2 Activity Limitations and Participation Restrictions

Findings from retrieved studies were mapped to seven of the nine chapters within the Activities and Participation component, with the exception of learning and applying knowledge, and mobility. The chapters with mapped findings are discussed below.

a) General tasks and demands. In this chapter, the ability to handle stress was identified as being affected by having a relative with aphasia.

b) Communication. Perhaps surprisingly, only two findings were linked to the communication chapter. Family members were found to have difficulty in conversing and discussing with the person with aphasia. This demonstrates that though aphasia is a communication disorder that can affect many areas of the family members' lives, their own communication is not affected with the exception of when communicating with the person with aphasia. This is obviously a significant change for close family members who communicate with the person with aphasia on a daily basis.

c) Self care. Two reports showed that family members experienced changes to their own self-care including alterations to their eating habits and maintaining their own health. This is noteworthy, as it seems probable that reduction in ability to maintain one's own health may have a negative impact on health, and could potentially contribute to the development of a health condition.

d) Domestic life. Many aspects of domestic life had changed for family members of people with aphasia as they took on more responsibility in the household and supported the person with aphasia in completing their daily activities, particularly those requiring verbal or written communication such as shopping, preparing food, and communicating with medical professionals.

e) Interpersonal interactions and relationships. Though family members did not experience changes to their communication with anyone besides the person with aphasia, many study findings demonstrated how family members experienced changes to their interpersonal relationships. Most reported negative changes to the social life of family members with less time for friends and social activities as well as changes to relationships within the family. When the family members under study were spouses of the person with aphasia, changes to marital satisfaction and sexual relationships were found.

f) Major life areas. Major life areas that were affected included changes to family member's employment, education, and volunteer work. Twelve studies

reported that family members had taken a larger role in the managing of the household finances.

g) Community, social and civic life. Negative changes to recreational activities were reported as some family members found decreased time for leisure activities. Other findings included poor social functioning and withdrawal from social situations. Some of the changes in interpersonal interactions and relationships were also reflected in the chapter of community, social and civic life. For example, family members' reports of loss of friends and less time for friends are likely associated with reports of less time for poor social functioning, and withdrawal from social situations.

When family member reports are mapped to the ICF, it becomes apparent that aphasia can impact upon most areas of a family member's functioning, and may conceivably lead to the development of a health condition. The ways in which family members from included studies have been affected by having a relative with aphasia are similar to those reported in past reviews (e.g., communication changes, social isolation, loss of sexual relationships, etc.) These findings also build upon previous knowledge with the identification of other ways that family members are affected (e.g., feelings of stress and sadness; difficulty maintaining one's own health; increased role in managing household finances, etc.) and clarify the range of third-party disability experienced by family members of people with aphasia through mapping to the ICF.

### 2.5.3 Implications for family-centred care

This study facilitates a more comprehensive understanding of third-party disability with implications for the provision of family-centred care. In particular, by describing the scope of the impact of aphasia on family through mapping to the ICF, areas of Impairment, Activity Limitation, and Participation Restriction were identified. This supports the development of intervention programs specific to the type of disability incurred by family members. According to the summary provided by this review, family members may require intervention to assist with changes that

occur in the areas of emotions, conversing with the person with aphasia, assisting others, relationships, social life, and financial management. The range of outcome measures revealed in this review may assist clinicians in identifying areas of rehabilitation need. However, none of these measures have the ability to expose the complete range of changes to family members' functioning and disability as summarized in this review highlighting the need for the development of more comprehensive outcome measures. In addition, further research in this area is needed to establish the best ways to support family members to cope with third-party disability and to determine the effectiveness of intervention programs.

### 2.5.4 Methodological considerations of this review

This systematic review demonstrated validity, clearly presented results, and relevance to the target population of family members of people with aphasia (Critical Appraisal Skills Programme, 2003). The inclusion of qualitative, quantitative, and mixed methods studies was a strength of this review, as was the inclusion of studies from many countries and representing a wide range of family member characteristics. However, some limitations of this review should be acknowledged. In restricting our search to peer-reviewed journal articles, less rigorous sources (e.g., book chapters, conference proceedings, commentaries, etc.) were excluded. Hand-searching of journals and reference lists was also not undertaken and may have resulted in some relevant studies being omitted. In addition, only English language studies were included in this review. Our decision to include all identified studies that met the inclusion criteria, regardless of quality, may also be viewed as a limitation. However, taken together the cumulative results of this review are indicative of the possible negative outcomes for family members and since many of these findings were based on small sample sizes, these results should be investigated further to confirm their contribution to third-party disability in aphasia. In addition, these results do not provide an indication of the severity of the disability incurred by family members. Areas for future research based on the findings and limitations of this systematic review, are discussed in the following section.

## 2.6 DIRECTIONS FOR FUTURE RESEARCH

### 2.6.1 Establishing the nature and degree of third-party disability in aphasia in the context of the ICF

Though these results provide a summary of the current literature demonstrating how third-party disability from aphasia can have a significant impact on the functioning of family members, the extent of the problem for individual family members remains unclear. Data synthesis showed that many of the findings were supported by only a small number of studies, reducing confidence in the degree to which these findings are generalisable. Future studies should establish the nature and degree of third-party disability with a sequential mixed methods approach whereby the results of inductive research are confirmed through deductive research with a larger number of participants for generalisation (Giddings & Grant, 2009).

The ICF is an internationally accepted framework for conceptualising disability (WHO, 2001). As such, it provides an appropriate starting point for investigating the under-developed concept of third-party disability (Scarinci, et al., 2009; Threats, 2010; WHO, 2001; Worrall & Hickson, 2008). Use of the ICF may facilitate a more comprehensive understanding of third-party disability, with implications for the development of intervention programs for family members that are specific to the type and level of disability. The international recognition of the ICF may also lead to improved funding for these services.

The limitations we identified in mapping to the ICF are consistent with those raised by Reed et al., (2005), Scarinci et al., (2009), Threats (2007), and Threats and Worrall (Threats & Worrall, 2004) who all reported difficulties with ambiguous or broad terminology used in the ICF. In future research, some of this difficulty can be overcome with the completion of *The Procedural Manual for the Standardized Application of the ICF: A Manual for Health Professionals* currently being developed jointly by the American Psychological Association and the World Health Organization.

### 2.6.2 Identifying factors that affect the development of third-party disability

Future observational studies should consider research design and the inclusion of specific variables to better understand the progression and predictors of third-party

disability. Most of the studies included in this review are cross-sectional in nature. Prospective longitudinal studies would provide a more valid description of how third-party disability evolves over time as people with aphasia recover and family members learn to adapt to their condition. Furthermore, it is valuable to follow the same individuals over time to identify individual factors that contribute to third-party disability. Variables of interest may be whether the family member lives with the person with aphasia (Franzén-Dahlin, et al., 2008), the strength of the relationship between the person with aphasia and the family member (Hemsley & Code, 1996), family member's coping style (McGurk, et al., 2011), the gender of the family member (Choi-Kwon, et al., 2005), the family's prior experience with disability (Hancock, 2011), characteristics of the family system (Lapointe, 2011) and the family member's personality (Threats, 2010). Another factor that is not well understood by the current research is the influence of the subtype and severity of aphasia on family members. Some researchers have observed a correlation between outcomes for family members and level of stroke-related disability, but the results are not specific to the disability caused by aphasia (Jönsson, Lindgren, Hallström, Norrving, & Lindgren, 2005; Ozge, et al., 2009; Schulz, Tompkins, & Rau, 1988).

It will also be valuable to understand how environmental factors contribute to the development of third-party disability in aphasia. Several studies in this review identified environmental factors that may be of interest. For example, some researchers have found that family members experience a decrease in emotional and psychosocial well being over time (Hemsley & Code, 1996; Herrmann, Britz, Bartels, & Wallesch, 1995; Kinsella & Duffy, 1978) and may need more support when the person with aphasia returns home from rehabilitation (Dalemans, et al., 2010). These factors are classified by the ICF in the second chapter of the environmental factors component, natural environment and human-made changes to environment and may be best explored through longitudinal studies.

Services, systems, and policies are environmental factors that may influence family members, such as support and information from health professionals (Denman, 1998; Michallet, et al., 2001; Nätterlund, 2010). For example, family members may benefit when the person with aphasia participates in therapy (Herrmann, et al.,1995), and when the family member is considered a partner in rehabilitation (Michallet, et al., 2001). Speech-language pathologists have been identified as the most appropriate

professional for supporting family members of people with aphasia (Soren-Peters, 2004; Rice, Paull, & Muller, 1987). However, as previously discussed, speech-language pathologists face barriers to their provision of care including insufficient time, resources, and professional training or experience. These barriers exist despite studies that provide empirical evidence for intervention with family members, underscoring the need for a development of intervention methods that are based on our understanding of third-party disability and dissemination of this information through clinical training. Also of interest is the influence of the environmental factor of support and relationships on the third-party disability of family members. For instance, an existing social support network and a flexible employer may be facilitators to health (Le Dorze, et al., 2009), while lack of support from other family members may be a barrier (Denman, 1998). Future intervention studies may provide more information about how support groups and counselling may lessen the effect of aphasia on family members (Pound, Parr, & Duchan, 2001; Rice, Paull, & Muller, 1987).

### 2.6.3 Distinguishing the influence of aphasia from the influence of stroke

A persistent difficulty in answering the research question was in distinguishing between the influence of aphasia and the influence of the stroke or other life events. Though some comparison studies have shown a greater burden from aphasia than other stroke-related deficits, it can be difficult to discern the specific influence of aphasia on family members, particularly since these events occur simultaneously.

Authors of two of the included studies have also reported on the issue of attributing changes that family members experience as being solely due to aphasia (Barrow, 2008; Le Dorze & Signori, 2010). Even in studies designed for comparison it can be problematic to isolate the effect of aphasia compared to other stroke-related deficits that may also affect family members such as mobility and behavioural changes (Bakas, et al., 2006). Since aphasia most often occurs in the context of other stroke-related deficits, the problem of attribution may not be easily resolved. Methods to isolate the effects of aphasia may include asking participants with aphasia to specifically note the changes to their lives that occurred because of aphasia as

opposed to changes that resulted from the stroke as a whole or other life changes. Appropriate comparison groups can be used to better isolate the impact of aphasia in quantitative research. This vein of research has theoretical implications as it may help to clarify the confusion between body function codes and personal factors, such as optimism that develops in response to the onset of a relative's aphasia as opposed to a pre-existing optimistic personality trait (Threats, 2007). However, determination of the origin of third-party disability (i.e., due to aphasia or stroke or both) may not be relevant in rehabilitation planning when the consequences of aphasia, in the context of stroke, need to be accounted for in responding to the overall needs of family members.

### 2.6.4 Third-party disability in children of people with aphasia

While studies have included the adult children of people with aphasia (Bakas, et al., 2006; Le Dorze, et al., 2009), very little attention has been paid to the effect of aphasia on non-adult children. This review includes only one article that acknowledges the effect of aphasia on a child. Though the focus of Barrow's report is the person with aphasia, the article does mention that her 14-year-old son experienced changes to his mental functions (i.e., sadness and confusion) secondary to his mother's aphasia (Barrow, 2008). The study of young children of people with aphasia is another area that warrants further investigation.

## 2.7 CONCLUSION

This systematic review reveals that family members of people with aphasia experience negative changes to their functioning and disability as reflected in the Body Functions, and Activities and Participation components of the ICF. While this review provides insight into the impact of aphasia on family members, it also underscores the need for future research. Clarification of the nature and extent of disability resulting from aphasia is important, particularly to determine how third-party disability may lead to the development of a health condition or a disease, such as depression. Further investigation into third-party disability in aphasia is vital for establishing evidence-based intervention for family members, the "hidden victims" of aphasia.

# CHAPTER 3

## THIRD-PARTY FUNCTIONING IN APHASIA – A SYSTEMATIC REVIEW OF THE POSITIVE EFFECTS OF APHASIA ON FAMILY MEMBERS[2]

---

**Grawburg, M., Howe, T., Worrall, L., & Scarinci, N. (2012). A systematic review of the positive outcomes for family members of people with aphasia.** ***Evidence-Based Communication Assessment and Intervention, 6*****(3), 135-149.**

[2]This chapter is an adaptation of the manuscript, entitled "A systematic review of the positive outcomes for family members of people with aphasia" published in Evidence-Based Communication Assessment and Intervention in 2012 and is inserted as accepted for publication, with the exception of the addition of recent references, and modifications to the text to ensure consistency and relevance to the current chapter and thesis.

## 3.1 ABSTRACT

Background: In the previous chapter, the literature revealing the negative effects of aphasia on family members was presented in the context of the ICF, demonstrating our current understanding of third-party disability in aphasia. Investigation of both the positive and negative effects of aphasia on family members is important for providing a holistic description of the experiences of family members.

Purpose: A systematic review of the literature was conducted to determine the positive effects of aphasia, the communication disorder, on family members with findings categorized according to the International Classification of Functioning, Disability and Health.

Method: The Cochrane Library, CINAHL, PsycINFO, and PubMed were searched for peer-reviewed studies reporting on the positive outcomes of aphasia on family members. Relevant findings were extracted from studies that met the inclusion criteria and then categorized according to the ICF.

Results: Though no studies have specifically aimed to examine the positive effects of aphasia on family members, it was possible to extract positive outcomes from studies that describe the overall impact of aphasia on family members. The results showed that family members of people with aphasia experience positive outcomes that can be linked to the Body Functions and Activities and Participation components of the ICF. Results are discussed in the context of the ICF and the influence of positive factors on the development of third-party disability.

Conclusion: While this review reveals some of the ways in which family members of people with aphasia can experience positive changes to their lives, it also highlights the need for further investigation in this area.

## 3.2 INTRODUCTION

The term post-traumatic growth has been used to describe the positive changes an individual experiences as a consequence of trauma, such as changes in themselves, changes in their relationships, and/or changes in their philosophy of life (Tedeschi & Calhoun, 2004). In addition to acknowledging negative outcomes that can occur due to a health condition, an understanding of the positive outcomes or post-traumatic growth, that occurs following the onset of aphasia will contribute to a more complete picture of an individual's experience. It is widely acknowledged that aphasia not only affects the person with aphasia but also their family members. The literature has repeatedly shown that family members experience changes to their lives due to their relatives' aphasia. For example, studies have revealed that family members experience role changes (Choi-Kwoon, et al., 2005; Herrmann, et al., 1995), increased caregiving duties (Bakas, et al., 2006; Le Dorze & Signori, 2010), the added responsibility of assisting the person with aphasia with communication (Gillespie, et al., 2010; Le Dorze & Signori, 2010), and changes to their social and recreational activities (Herrmann, et al., 1995; Kinsella & Duffy, 1979; Le Dorze & Signori, 2010). However, the majority of these reports focus on the negative outcomes associated with aphasia and overlook positive outcomes.

Increasingly, researchers are recognizing the need for a better understanding of the positive outcomes for family members. This is particularly true in the caregiver burden literature where authors have highlighted the importance of a holistic examination of the consequences for family members with implications for rehabilitation and theory (Kramer, 1997; McKee, et al., 2003; Rapp & Chao, 2000; Toljamo, Perälä, & Laukkala, 2012). In rehabilitation, consideration of both positive and negative outcomes will facilitate the development of the most appropriate support strategies for family member members and maximize the effectiveness of intervention (Kramer, 1997; McKee et al., 2003). In addition, an awareness of the positive changes associated with having a relative with a health condition may also contribute to a better understanding of protective factors in caregiving (Greenwood, et al., 2008; Mackenzie & Greenwood, 2012; Toljamo et al., 2012). In fact, theories about caregiving may be inaccurate, and certainly incomplete, if positive outcomes are not taken into account (Kramer, 1997).

Studies of family members of people with stroke have yielded some evidence of positive outcomes, which can co-occur along with negative changes. In a recent systematic review, Mackenzie and Greenwood (2012) reported that family members experienced a broad range of positive outcomes associated with stroke caregiving that changed over time. Two other systematic reviews have also identified positive outcomes for family members (Greenwood, Mackenzie, Cloud, & Wilson, 2009; Han & Haley, 1999). Specifically, family members experienced positive emotional changes such as increased pride (Burman, 2001; Clemson, Fitzgerald, & Mullavey-O'Byrne, 1999), a sense of feeling good (Johnson, 1998), and appreciation (Haley, et al., 2009). There were reports of positive changes to the family members' relationships, most commonly in their relationship with the person with stroke, such as feeling closer to them (Bacon, Milne, Sheikh, & Freeston, 2009; Haley, et al., 2009; Moore, Maiocco, Schmidt, Guo, & Estes, 2002; Secrest, 2000; Subgranon & Lund, 2000) and working together (Pierce, Steiner, Thompson, Govoni, & Friedemann, 2007) (White, et al., 2007). In addition, family members had positive perceptions of caregiving, such as enjoyment, satisfaction, and fulfilment derived from helping others (Bacon, et al., 2009; Johnson, 1998; Moore, et al., 2002; Subgranon & Lund, 2000). In the Auckland Regional Community Stroke Study, family members of people with stroke also experienced improvements in their relationship with the person with stroke and increased self-esteem (Parag, et al., 2008). The authors of these three review studies have indicated that further investigation into the positive outcomes for family members of people with stroke is needed (Greenwood, et al., 2009; Han & Haley, 1999; Mackenzie & Greenwood, 2012).

Many authors have suggested that the effect of aphasia on family members should be considered separately from other stroke-related deficits, as communication difficulties can result in different outcomes, possibly more severe outcomes, for family members (Artes & Hoops, 1976; Bakas et al., 2006; Franzén-Dahlin et al., 2008; Le Dorze & Brassard, 1995). Of the studies described above that revealed positive outcomes for family members of people with stroke, the effects on family members of people with aphasia were not analysed independently from those family members of people with stroke without aphasia, so it is impossible to discern the positive outcomes that may be attributable to aphasia and not other stroke-related

deficits. Three systematic reviews have been conducted that aimed to investigate the effect of aphasia on family members, however, none reported any positive outcomes (Servaes, et al., 1999; Rombough, et al., 2006; Rombough, et al., 2007). Thus, the importance of an appreciation of the positive outcomes for family members of people with aphasia is clear and an up-to-date summary of the current literature is required.

The International Classification of Functioning, Disability and Health (ICF) is a framework that describes how Functioning and Disability result from the dynamic interaction between an individual's health condition and Contextual Factors (WHO, 2001). Functioning and Disability are comprised of the components of Body Functions and Structures and Activities and Participation; Contextual Factors include the components of Environmental Factors and Personal Factors. These components are subdivided into domains that can be used to describe an individual's Functioning and Disability. In the ICF, Functioning is an overarching term that includes Body Functions, Activities and Participation; while Disability includes Impairments of Body Functions, Activity Limitations, and Participation Restrictions. Third-party disability is defined in the ICF as the changes in functioning and disability family members experience as a consequence of a relative's health condition. Both positive and negative outcomes experienced by family members of people with aphasia likely contribute to changes in their Functioning and Disability and, thus, the development of third-party disability. Descriptive health-related information, such as outcomes for family members, is frequently linked to the ICF in order to capitalize on its common language and bio-psychosocial approach to provide a context for categorizing findings (Fayed, Cieza, & Bickenbach, 2011). As such, the ICF provides a standard for classifying and synthesizing the findings from this systematic review. The aim of this systematic review is to synthesize the current literature on the positive effects of aphasia on family members by categorising these findings according to the terminology of the ICF.

## 3.3 METHOD

### 3.3.1 Search procedures

To address the aim of this systematic review, The Cochrane Library, CINAHL, PsycINFO, PubMed, and Web of Science were searched from their earliest

possible date with an end date of September 1, 2013. The following search terms were applied: (family OR families OR spouse* OR carer* OR caregiver* OR son OR sons OR daughter* OR husband* OR wives OR wife OR parent* OR mother* OR father* OR sibling* OR sister* OR brother*) AND (aphasia OR dysphasia). When medical subject headings were available, they were included and combined.

### 3.3.2 Inclusion and exclusion criteria

To be included in the review, the article must have met the following criteria: a) describe how aphasia positively affects family members, b) involve participants with aphasia only acquired secondary to stroke, c) include family members who may be described using various terminology such as caregivers or carers, as long as they are unpaid, d) be peer-reviewed, e) involve qualitative, quantitative, or mixed methods descriptive studies with original data, and f) be published in English. Articles were excluded if they were presented as commentary, narrative (i.e., personal stories not analysed in a systematic way), unpublished dissertations, or conference presentations, they were intervention studies, or if they did do not distinguish aphasia from other communication disorders or clearly separate the consequences of aphasia from the consequences of stroke in the analysis and interpretation of the findings.

### 3.3.3 Selection procedure

Author(s) independently identified articles likely to be relevant to the research question based on the title. Subsequently, abstracts and full text were reviewed to determine if the studies met the inclusion criteria. For articles published prior to August 10, 2011, the article selection process was conducted by 2 authors with any discrepancies discussed to reach consensus. Studies published between August 11, 2011 and September 1, 2013 were selected only by the candidate, according to the same criteria. Nine studies were accepted as meeting the inclusion criteria for the review.

### 3.3.4 Methodological quality assessment

Each accepted article was appraised using a quality assessment tool developed for the purpose of concurrently assessing qualitative, quantitative, and mixed methods studies in the health sciences (Pluye et al., 2012). For articles published prior to August 10, 2011, two authors (MG and TH) independently assessed the content of each article. Any discrepancies in scoring were discussed until consensus was reached. Only the candidate assessed the content of articles that were published between August 11, 2011 and September 1, 2013. Though inter-rater agreement was not measured specifically for this review, the reliability of this quality assessment tool has been previously calculated and found to be reliable with an Intra-Class Correlation of 0.8 (Pace, et al., 2010). Articles were not omitted based on low quality due to the small number retrieved. The quality rating for each article is displayed as a percentage in Table 3.1.

### 3.3.5 Data extraction & synthesis

In cases of articles published prior to August 10, 2011, three authors (MG and TH or LW) scanned the articles for findings that identify how family members were positively affected by having a relative with aphasia. Relevant findings were agreed upon through discussion and extracted for data synthesis. For articles published between August 11, 2011 and September 1, 2013, data were extracted by the candidate only.

Following a process based on thematic synthesis as described by Dixon-Woods, et al. (2005), similar findings were grouped into categories. For example, ‘decreased conflict with spouse over daily decisions’ and ‘paying more attention to spouse’ were categorized together under improved relationship with spouse.

Next, the categories were linked to the categories of the ICF with adherence to ICF linking rules (Cieza et al., 2005). Other authors have used similar linking procedures to organize and synthesize date retrieved from systematic reviews (see Fayed, et al., 2011 for a review). Classification of the results was conducted by the first author (MG) and mutually agreed upon through discussion with the other authors.

## 3.4 RESULTS

The search resulted in nine studies being retrieved that met the inclusion criteria. Table 3.1 provides a summary of these studies including the study aim and design, methodological quality rating, participant details, positive outcome measures, and key findings related to the aim of this review.

Five countries were represented in the included studies. Six studies were qualitative, two were quantitative, and one was mixed methods. Five were longitudinal, with the other four being cross-sectional in nature. Positive outcomes were extracted from qualitative interviews, participants' diaries, questionnaires, and the Marital Comparison Level Index (a measure of marital relationship outcomes relative to expectations).

Of the included studies, three aimed to describe how aphasia affects family members, while another three investigated recovery, adaptation, and/or coping of family members and/or people with aphasia. Of the last three studies, one looked at the attitudes of family members of people with aphasia, one measured the effect of aphasia on marital satisfaction, and the last explored the changes to the sexual relationship between spouses where one has aphasia. None of the studies specifically stated their purpose was to examine the positive effects of aphasia on family members, though one study did investigate family members' perspectives about how to live successfully with aphasia.

Post-onset of aphasia ranged between 1-week and 11-years. Sample sizes of family member participants ranged from 1 to 40 people. One study did not include information about the relationship of the family member to the participant with aphasia, nor the gender of the family members. In most studies, the family member was the spouse of the participant with aphasia, however, parents, siblings, children, and a friend were also included in one study, and daughters were the exclusive family member participants in another. The majority of family member participants were female.

Table 3.1.

*Summary of studies describing positive changes (third-party functioning) experienced by family members of people with aphasia.*

| Year<br>Author<br>Country | Study aim<br>Study design<br>Quality rating | FM details<br>Sample size; Response rate; % female; Mean age (range); Relationship to the PWA | PWA details<br>Sample size; Time post-onset; % male; Mean age (range) | Positive outcome measures | Key findings –<br>Positive outcomes experienced by FMs of PWA |
|---|---|---|---|---|---|
| 2011*<br>Brown, Worrall, Davidson, & Howe<br>Australia | Aim: To identify family members' view on living successfully with aphasia<br>Design: Qualitative, cross-sectional<br>Quality rating: 100% | n=24; 92% response rate; 62.5% female; Spouse (79%), parent (12.5%), brother (4%), daughter (4%) | n=23; time post-onset not stated; 52% male; mean age=62.5% (range=40-86) | Semi-structured in-depth interviews. | Positive effects of aphasia on FMs were increased appreciation, belief in oneself, working with other FMs, putting life in perspective, and realizing own strength. |
| 2010<br>Pringle, Hendry, McLafferty, & Drummond<br>UK | Aim: To understand the experience of returning home after stroke, from the perspective of PWA and their FMs.<br>Design: Qualitative, Longitudinal.<br>Quality rating: 50% | n=4, response rate not stated; % female not stated; Age not stated; Relationship to PWA not stated | n=4; 1 month post-onset; % male not stated; Age not stated | In-depth interviews; self-report diaries | FMs reported increased appreciation for small pleasures and recognizing the importance of keeping hope alive. |

| | | | | | |
|---|---|---|---|---|---|
| 2009<br><br>Le Dorze, Tremblay & Croteau<br><br>Canada | Aim: To describe an adult daughter's adaptation to her father's aphasia.<br><br>Design: Qualitative, Longitudinal<br><br>Quality rating: 100% | n=1; Response rate not applicable; 100% female; 31 years; Daughter (100%) | n=1; During the first year post-stroke (before and after outpatient rehabilitation and 3 months later); 100% male; 60 years | Semi-structured, in depth, face-to-face interview | The FM felt useful and described herself as "driven by curiousity", "protective", and "determined" in relation to her father's aphasia. |
| 2009<br><br>Nätterlund<br><br>Sweden | Aim: To investigate close relatives' perceptions of the influence of aphasia on their own life.<br><br>Design: Qualitative,<br><br>Cross-sectional<br><br>Quality rating: 50% | n=14; 70% response rate; 50% female; Age not stated; Spouse (50%), parent (29%), sibling (7%), child (7%), friend (7%) | n=14; 2-11 years post-onset;64% male; Mean age=55.6 years (range=28-70) | Interviews | FMs reported increased self confidence secondary to fighting for how things were before. They also made new friends. |
| 2003<br><br>Michallet, Tétreault, & Le Dorze (2003)<br><br>Canada | Aim: To determine the consequences of severe aphasia on the spouses of PWA<br><br>Design: Qualitative, Cross-sectional<br><br>Quality rating: 100% | n=5; Response rate not stated; 80% female; Mean age=66 years (range=59-71); Spouses (100%) | n=5; post-onset time not stated; 80% male; Mean age=69 years (range=64-77) | Qualitative interviews | 60% of couples reported improvement in their relationship between the FM and PWA (e.g., love between FM and PWA was emphasized by communication difficulty and hardship, couples paid more attention to one another and showed each |

| | | | | | |
|---|---|---|---|---|---|
| | | | | | other more affection, communicating with the PWA was more pleasant for the FM). |
| 2001<br><br>Lemieux, Cohen-Schneider, & Holzapfel<br><br>Canada | Aim: To investigate how sexuality changed for couples post-onset of aphasia.<br><br>Design: Qualitative,<br><br>Cross-sectional<br><br>Quality rating: 25% | n=6; 25% response rate; 83% female;<br><br>Age not stated;<br><br>Spouse (100%) | n=6; 1-3 years post-onset; 83% male;<br><br>65 years (range=53-70) | Joint structured questionnaire with PWA<br><br>35-item written questionnaire | For 33% of couples there was an increase in genital touching. 50% of couples reported an increase in caressing, hugging and kissing. |
| 1995<br><br>King & Shade-Zeldow<br><br>USA | Aim: To compare the process of adapting to a partner's stroke with and without aphasia.<br><br>Design: Mixed methods, Longitudinal, Comparison<br><br>Quality rating: 50% | n=15; 61% response rate; 67% female; Mean age not stated, but 60% were over 56 years; Spouse (100%) | n=20; Prior to rehabilitation discharge, 6-weeks, 10-weeks, and 1-year post-discharge; Gender not stated; Age not stated | Open-ended interview guide | 57% of FMs reported 1 or more of the following positive outcomes: finding meaning in life, personal growth, improved relationship with PWA and other FMs, and positive health impact. |
| 1993 | Aim: To measure the impact of aphasia on marital satisfaction | n=40; Response rate not stated; 83% female; Age | n=40; 1 month - 30 years post-onset; 83% | Marital Comparison | A few FMs reported positive changes to their marriage in the following areas: time |

| | | | | | |
|---|---|---|---|---|---|
| Williams<br><br>USA | Design: Quantitative, Cross-sectional/ retrospective<br><br>Quality rating: 75% | not stated; Spouse (100%) | male; Mean age=68 years (range=44-75) | Level Index | spent together, conflict over daily decisions, arguing over petty issues, conflict over the use of leisure time, conflict over spending money, jealousy expressed by spouse, and<br><br>the amount of privacy experienced. |
| 1970<br><br>Malone, Ptacek, & Malone<br><br>USA | Aim: To measure the frequency and intensity of attitudes of spouses of PWA.<br><br>Design: Quantitative,<br><br>Cross-sectional<br><br>Quality rating: 0% | n=30; Response rate not stated; 67% female; Mean age=48 years (range=24-63;<br><br>Spouse (100%) | n=30; 6 months to 3 years post-onset; Gender not stated; Age not stated | Questionnaire designed by researchers | 33% reported participating in social activities more, 17% entertained more, 10% visited more, 13% vacationed more. |

FM=family member, PWA=person with aphasia

* Paper added when this review was updated with publications retrieved between August 11, 2011 and September 1, 2013.

### 3.4.1 Data synthesis through linking to the ICF

Positive outcomes were extracted and linked to the ICF. The results are displayed in Table 3.2, which includes details of the ICF category, ICF code, and the corresponding effect on the family member. Synthesis of the findings show that the positive effects of aphasia on family members can be linked to the Body Functions and the Activities and Participation components. Within the Body Functions component, ‘appreciative’ and ‘hopeful’ were linked to the Mental Functions chapter. In the Activities and Participation component, three findings were linked to each of the Interpersonal Interactions and Domestic Relationships chapter and the Community, Social and Civic Life chapter. Additional positive outcomes that were not clearly linked to the Functioning and Disability part of the ICF were either designated as ‘not definable-general health’ or ‘not definable-quality of life’. These codes are displayed along with the family member report in Table 3.3. A discussion of issues that arose when linking family member reports to the ICF follows in the next section.

Table 3.2.

*Synthesis of the positive findings mapped to the ICF: Third-party functioning in aphasia according to the existing literature.*

| ICF Component | ICF Chapter | ICF Category | ICF Code | ICF Code Name | Corresponding effect on family member | References |
|---|---|---|---|---|---|---|
| Body Functions | Mental Functions | b126 Temperament and personality functions | b1265 | Optimism | Hopeful | Le Dorze, Tremblay, & Croteau (2009); Pringle, Hendry, McLafferty & Drummond (2010) |
| | | b152 Emotional functions | | | Appreciative | Brown, Worrall, Davidson, & Howe (2011); Pringle, Hendry, McLafferty & Drummond (2010) |
| Activities and Participation | Interpersonal interactions and domestic relationships | d760 Family relationships | | | Improved relationship with other family members | Brown, Worrall, Davidson, & Howe (2011); King & Shade-Zeldow (1995) |
| | | d770 Intimate relationships | d7701 | Spousal relationships | Improved relationship with PWA (spouse) | King & Shade-Zeldow (1995); Michallet, Tétreault, & Le Dorze (2003); Williams (1993) |
| | | | d7702 | Sexual relationships | More physical affection/ physical intimacy between family member and person with aphasia | Lemieux, Cohen-Schneider, & Holzapfel (2001); Michallet, Tétreault, & Le Dorze (2003) |

| | | | | | | |
|---|---|---|---|---|---|---|
| | | | | | (spouses) | |
| | Community, social and civic life | d910 Community life | d9100 | Informal associations | More participation in social activities, entertained more, visited more | Malone, Ptacek, & Malone (1970) |
| | | | | | Made new friends | Natterlünd (2009) |
| | | d920 Recreation and leisure | | | More vacations | Malone, Ptacek, & Malone (1970) |

Table 3.3.

*Positive effects of aphasia that could not be mapped to the ICF.*

| Category | ICF Code | Effect on family member | References |
|---|---|---|---|
| Not definable-general health | nd-gh | Positive impact on health | King & Shade-Zeldow (1995) |
| Not definable-quality of life | nd-qol | Realize own strength | Brown, Worrall, Davidson, & Howe (2011) |
| Not definable-quality of life | nd-qol | Reassess one's priorities | Brown, Worrall, Davidson, & Howe (2011) |
| Not definable-quality of life | nd-qol | Finding meaning in life | King & Shade-Zeldow (1995); Natterlünd (2009) |

## 3.5 DISCUSSION

While there have been a significant number of investigations exploring the negative outcomes of aphasia on family members, fewer studies have revealed the positive effects of having a relative with aphasia. In this systematic review, nine studies were retrieved that reported positive outcomes for family members of people with aphasia. This is a relatively small number of studies with proportionately small number of extracted findings; however, this review does provide an important summary of the current literature, which is indicative of directions for future research.

### 3.5.1 Issues with linking findings to the ICF

A total of eleven findings were extracted from the included studies and mapped to the ICF. The majority of these findings were clearly linked to the ICF, however, there was a subset of findings that were less easily categorized. There was confusion over whether certain family member reports should be linked to the components of Body Functions, or Personal Factors, or be outside the scope of the ICF and coded as 'not definable-quality of life'. A detailed explanation of these difficulties is provided below in the interest of improving the ICF by transparently presenting concepts that are difficult to classify (Fayed, et al., 2011).

The issues in mapping to the ICF were related to the extracted findings of 'personal growth' and 'finding meaning in life.' On one hand, these findings may be linked to the Functioning and Disability part of the ICF, attributed to occurring as a result of the aphasia. On the other hand, they may be considered aspects of coping, experience, behaviour, and/or psychological assets, all of which are features of Personal Factors as described in the ICF (WHO, 2001). Threats (2007) acknowledged the confusion in the literature between these two areas of the ICF, specifically between the Body Functions and Personal Factors components, and indicated that if the change occurs as a result of the health condition, then it is most appropriately mapped as a change to Functioning and Disability (i.e., not as a Personal Factor). Thus, since these findings are attributed to a significant other's aphasia, they are best categorized within the domains of Functioning and Disability. However, upon further inspection, it seemed plausible that these family member reports could be considered

meaningful concepts related to quality of life, described as how an individual feels about the changes that occur to their Functioning as a consequence of a health condition (Cieza et al., 2005). Bearing in mind the limited number of examples for each family member report, it was not possible to determine with certainty how these findings relate to Functioning and Disability, and/or quality of life. Mapping of the ICF findings presented here are based on the evidence available, though may appropriately shift with the availability of data from future studies.

### 3.5.2 The influence of positive outcomes on the development of third-party disability

Findings linked to the Body Functions and Activities and Participation components of the ICF show that family members experience changes to their Functioning as a result of their relative's aphasia. Since the extracted findings are considered to be positive in nature, it is unlikely that these changes contribute to increased disability, however, they can impact on the development of third-party disability as the positive changes identified may lead to improved functioning or mitigate the effects of negative changes contributing to disability. It is evident that positive outcomes for family members could be influential factors in the development of third-party disability and should, therefore, be included in future research establishing the nature and degree of third-party disability. In the case of positive changes, the term third-party functioning, rather than third party disability may more adequately describe the experience of family members of people with aphasia.

### 3.5.3 Selection of appropriate measurement tools in future research

This systematic review highlights the need for future research exploring positive outcomes for family members of people with aphasia. In addition, the results suggest that studies use assessment tools that measure the full range of possible outcomes for family members to gain a more complete understanding of the impact of aphasia. The majority of the extracted positive findings in this review came from the investigations that used open-ended interviews as part of a qualitative or mixed methods design. Quantitative studies more often utilized questionnaires and surveys (e.g., the General Health Questionnaire and various depression scales) where the

purpose of the tool is to identify problems. Due to the nature of this method, positive outcomes would have been inadvertently excluded, as participants were unable to disclose information that was not requested of them.

Increasingly, tools are being developed and adapted to include items that measure both positive and negative outcomes. For example, the response options on the Bakas Caregiver Outcome Scale (Bakas et al., 2006) range from negative to positive (i.e., –3 = *Changed for the worst* to +3 = *Changed for the* best), the Caregiver Strain Index+ (Al-Janabi, Frew, Brouwer, Rappange, & Van Exel, 2010) was adapted from the original Caregiver Strain Index that measured only negative outcomes for caregivers, to include an additional 5 items measuring positive changes, and lastly, the Daily Caregiving Diary was developed with a section entitled Caregiver Gains to account for positive outcomes for family members (Bacon, et al., 2009). Use of tools such as these that allow for a range of positive, negative, and neutral responses from participants will further improve our understanding of the development of third-party functioning in family members.

This recommendation also holds true for the ICF itself. As a framework for conceptualising health and health-related states, the suggested coding for components of Functioning and Disability are heavily skewed towards the negative and thus emphasize changes in disability over functioning. This has the effect of misrepresenting the individual's experience by classifying changes in one direction only. As described in the ICF, the components of Functioning and Disability can be expressed to indicate problematic and non-problematic states of health, but non-problematic states of health are described as being neutral, not positive (WHO, 2001). That is, qualifiers within the Body Functions and Body Structures component represent levels of *impairment* (i.e., 0 =*No impairment* to 4 = *Complete impairment)* and qualifiers in the Activity and Participation component various levels of *difficulty* (i.e., 0 = *No difficulty* to 4 = *Complete difficulty*) (WHO, 2001). There are no codes that represent positive changes or improvements to Functioning. Within the Contextual Factors component, Environmental Factors are coded as either *facilitators* or *barriers*, depending on whether they have a positive or negative affect on an individual's performance (WHO, 2001). Unlike the qualifiers in the Activities and Participation component, these constructs are classified using both negative and positive terminology (i.e., 0 = *No barrier* to .4 = *Complete barrier*, 0 = *No facilitator*

to +4= *Complete facilitator)*. Though Personal Factors are not yet coded by the ICF, they are classified with Environmental Factors as components of Contextual Factors and might logically be coded in the same way. However, as Threats (2007) indicated, it may be difficult to establish whether aspects of personality are enduringly positive or negative as their influence may be situation specific. Though the ICF does state that users can adapt existing constructs to allow for positive changes, no examples are given so the ICF does not set a standard for coding positive aspects of functioning. Future research investigating positive outcomes for people with health conditions will advise on modifications about how best to represent positive changes in the ICF.

### 3.5.4 Implications for intervention

Knowledge of the positive outcomes of aphasia on family members is vital for planning targeted intervention and providing appropriate support. Consideration and inclusion of the positive changes experienced by family members into intervention planning is consistent with the strength perspectives approach to rehabilitation (Saleebey, 2009). The strengths perspective is a philosophy based in social work that involves collaboration between clients and clinicians to build on the client's strengths, capacities, and competencies to maximize quality of life (Saleebey, 2009). In the strengths perspective, caregiver burden experienced by family members is recognized as an issue with recommendations to include family members in the process of establishing care through dialogue, ongoing assessment of perceived burden, and role adjustment (Nelson-Becker, Chapin, & Fast, 2009). Attention to positive outcomes in the context of the strengths perspective has been discussed by Worrall (2000) as a guide for functional communication therapy, however its usefulness can be extended beyond the person with aphasia to provide an orientation towards rehabilitation of family members. Awareness of positive outcomes can reduce the chance that beneficial changes will be overlooked or go unacknowledged in the development of (Worrall, 2000) a rehabilitation plan. Instead, positive changes can be strengthened and enhanced with a focus on minimization of negative outcomes. For example, results from this review demonstrate that speech-language pathologists should be aware that family members may experience positive changes in their relationships with the person with aphasia, other relatives, and their friends. Speech-language pathologists can use knowledge of these positive relationship changes as a resource when planning intervention and counselling family members (e.g., by discussing

existing supportive relationships and/or opportunities to develop new relationships, such as through aphasia support groups).

### 3.5.5 Limitations

Limitations of this review include threats to reliability due to lack of inter-rater agreement data for study selection, data extraction, and methodological quality assessment. Instead, a consensus-building process was used where authors discussed any discrepancies to reach agreement (Schlosser, et al., 2007). In addition, publication bias is possible as only published articles were included (Easterbrook, Berlin, Gopalan, & Matthews, 1991) and unpublished studies may have contributed different results (Egger & Davey Smith, 1998). For example, given the relatively recent interest in positive outcomes for family members, studies that reported negative outcomes may have been more frequently published. Finally, language bias is also possible as only articles published in English were included.

## 3.6 CONCLUSION

The results of this systematic review show that family members of people with aphasia do experience some positive outcomes as a consequence of their relative's aphasia. When interpreted in the context of the ICF, data synthesis reveals that positive family member reports can be linked to the Body Functions and the Activities and Participation components of the ICF, illustrating that family members experience a change in their Functioning as a consequence of aphasia. These results contribute to our understanding of third-party disability (perhaps better termed third-party functioning) as positive outcomes may improve functioning or be protective against the development of disability.

This review is based on a small number of studies that have reported positive effects of aphasia on family members. Further research, explicitly aimed to investigate positive outcomes, will surely lead to additional evidence for the scope and degree of positive changes experienced by family members. Moving forward, it is vital that positive and negative effects of aphasia on family members are considered as both can contribute to changes to Functioning and Disability. This vein of research

will have substantial implications for our conceptualisation of third-party disability and the development of intervention programs.

# CHAPTER 4

## A QUALITATIVE INVESTIGATION INTO THIRD-PARTY FUNCTIONING AND DISABILITY IN APHASIA[3]

**Grawburg, M., Howe, T., Worrall, L., & Scarinci, N. (2013). A qualitative investigation into third-party functioning and third-party disability in aphasia: Positive and negative experiences of family members of people with aphasia.** ***Aphasiology, 27*****(7), 828-848.**

[3]This chapter is an adaptation of the manuscript, entitled "A qualitative investigation into third-party functioning and third-party disability in aphasia: Positive and negative experiences of family members of people with aphasia." published in Aphasiology in 2013 and is inserted as accepted for publication with modifications to the text to ensure consistency and relevance to the current chapter and thesis.

## 4.1 ABSTRACT

Background: In the International Classification of Functioning, Disability and Health (ICF), the World Health Organization introduces the term "third-party disability" and identifies the need for further investigation into family members' Functioning and Disability in relation to a significant other's health condition. The systematic reviews presented in the previous two chapters provided an overview of the current knowledge of third-party functioning and disability.

Aims: This qualitative investigation represents the first phase of a mixed methods study to develop a tool for measuring third-party functioning and third-party disability in aphasia. The aims of this phase of the study were to explore: 1) the positive aphasia related changes associated with third-party functioning, and; 2) the negative aphasia-related changes associated with third-party disability, as experienced by family members of adults with aphasia post-stroke.

Methods & Procedures: This study used an inductive design with a qualitative descriptive research strategy to explore the lived experience of having a relative with aphasia. Twenty family members (e.g., spouses, parents, children, siblings, etc.) of individuals with aphasia participated in individual in-depth semi-structured interviews. The interviews were analysed using qualitative content analysis.

Outcomes & Results: Analysis revealed five categories of positive aphasia-related changes associated with third-party functioning: (1) emotions; (2) communication; (3) relationships; (4) recreational activities and social life; and (5) paid/volunteer work or education. In addition, seven categories of negative aphasia-related changes associated with third-party disability were revealed: (1) physical, mental, and emotional health; (2) communication; (3) relationships; (4) recreational activities and social life; (5) paid/volunteer work or education; (6) domestic and caregiving responsibilities; and (7) finances.

Conclusions: Interpreted within the framework of the ICF, this study showed how the pervasive effects of aphasia are associated with changes in Functioning and Disability in family members, providing a holistic description of family members' experience using the standardized language of the ICF. Clinically, these results emphasize the importance of recognizing the positive and negative outcomes for close family members in the development of a rehabilitation plan for the family to address their experience of third-party disability.

## 4.2 INTRODUCTION

Due to the profound impact that chronic aphasia has on both the person with aphasia and their close family members, aphasia has been referred to as a family problem (Buck, 1968). For the past four decades, researchers have investigated how family members are affected by having a relative with aphasia, as well as their needs for rehabilitation. This research has revealed extensive bio-psychosocial consequences for family members. Specifically, family members have difficulty communicating with their relative with aphasia (Le Dorze, et al., 2009), experience changes in their relationship with them (Zemva, 1999), and in their relationships with other relatives and friends (Michallet, et al., 2003). Also affected are family members' employment (Salonen, 1995), domestic responsibilities (Michallet, et al., 2001), social activities (Herrmann, et al., 1995), and emotions (Christensen & Anderson, 1989). Furthermore, family members may experience mental health conditions, such as depression, as a consequence of their relative's aphasia (McGurk, et al., 2011).

Given the considerable impact of aphasia on family members, it is imperative that they be recognized as clients with their own requirements for rehabilitation (Visser-Meily et al., 2006). Indeed, family members have described their need to be involved in rehabilitation and suggested their own rehabilitation goals (Howe, et al., 2012). In addition, family members often act to support the person with the disability (WHO, 2011); thus, meeting the needs of family members may also facilitate a better outcome for the person with aphasia. Despite this, there is currently a mismatch between the needs of family members and the ability of speech-language pathologists to support them. Clinicians have indicated that they often do not have goals or have limited goals for family members (Sherratt, et al., 2011). They have also expressed concern about a lack of time and resources to support family members and provide appropriate treatment for addressing the broad consequences of aphasia (Johansson, et al., 2011; Law et al., 2010). Moreover, funding of rehabilitation programs may not be conducive to the inclusion of family members (Levack, Siegert, Dean, & McPherson, 2009). Thus, despite the extensive literature in this area, significant gaps in services for family members remain.

The International Classification of Functioning, Disability and Health (ICF) is an internationally recognized framework for describing health and disability (WHO, 2001). In the ICF, changes to Functioning and Disability occur as a consequence of

the dynamic interaction between an individual's health condition and Contextual Factors, such as Environmental Factors and Personal Factors. An individual's Functioning includes Body Functions, Activities and Participation; while Disability is described as Impairments to Body Functions, Activity Limitations, and Participation Restrictions. In the ICF, the term *third-party disability* is suggested to describe the effect of a significant other's health condition on family members' Disability (WHO, 2001). As the development of Disability is due to negative changes associated with a health condition, we propose that the term *third-party functioning* be used to describe positive and/or neutral changes to a family member's Functioning as a consequence of a significant other's health condition.

Scarinci and colleagues (2009) have developed a model based on the ICF to illustrate how spouses of people with hearing impairment develop third-party disability. The model shows that spouses experience changes to their Functioning and Disability as a consequence of their partner's hearing impairment (e.g., Activity Limitations such as difficulty communicating with their partner and Participation Restrictions like reduced social activities). It has been suggested that further research into third-party disability of family members of people with aphasia is warranted and that the ICF may be an appropriate framework for this investigation (Threats, 2010). We propose that a clear description of the third-party functioning and third-party disability experienced by family members of people with aphasia using the standardized language and framework of the ICF may lay the groundwork for improved resources, policies, and funding for people with aphasia and their family members.

Although a number of studies have investigated the impact of having a relative with aphasia, little research has used the ICF to describe the impact of aphasia on family members. Furthermore, very little research has been specifically conducted into third-party disability in aphasia. One exception is a study by Le Dorze and Brassard (1995) where the consequences of aphasia on family members were categorized in the context of the International Classification of Impairment, Disability and Handicap (ICIDH) (WHO, 1980). The ICIDH was the precursor to the ICF and used the terms impairment, disability, and handicap to describe the consequences of disease. In their study, family members' reports were categorized as handicaps if they prevented them from fulfilling their normal roles (Le Dorze & Brassard, 1995).

Handicaps identified included changes in family members' communication with their relative with aphasia, changes in their relationships with their relative with aphasia and their friends, changes in household routines, increased responsibility of caring for their relative with aphasia and assisting them to communicate, reduced social activities, and diminished interest in career. While the term third-party disability was not used, this study shows how the impact of aphasia on family members can be classified under a framework of health and disability.

Positive outcomes for family members of people with aphasia, including the concept of third-party functioning, have not been thoroughly investigated (Grawburg, Howe, Worrall, & Scarinci, 2012; Mackenzie & Greenwood, 2012). Positive consequences of any health condition form part of the complete picture of the experience of family members' functioning and disability with implications for assessment and rehabilitation planning (Kramer, 1997) and may be best identified through qualitative research, particularly in the absence of quantitative measurements tools that account for positive changes (Grawburg, et al., 2012; Greenwood, et al., 2009).

We have conducted two systematic reviews to consolidate the current literature regarding third-party functioning and third-party disability in aphasia (Grawburg, et al., 2012; Grawburg , Howe, Worrall, & Scarinci, 2013a). In these reviews, findings were synthesized according to the ICF to reveal a wide-range of effects of aphasia on family members in the Body Functions and Activities and Participation components. Gaps in the literature were also identified. In addition to a lack of investigation into the positive impact of aphasia on family members, few studies included the perspective of children and teenage family members of people with aphasia who are undoubtedly affected, but may have different outcomes related to Functioning and Disability than older family members (Grawburg, et al., 2012, 2013a).

## 4.3 AIM

This qualitative investigation represents the first phase of a mixed methods study to develop a tool for measuring third-party functioning and third-party disability in aphasia and establish the nature and severity of the effects of aphasia on family

members using the language and framework of the ICF. In this phase of the study, the specific research aims were to explore: 1) positive aphasia-related changes associated with third-party functioning; and 2) negative aphasia-related changes associated with third-party disability, as experienced by family members of adults with aphasia post-stroke.

## 4.4 METHOD

### 4.4.1 Design

As the first phase of a mixed methods study, this research was conducted within the post-positivist paradigm to expose evidence that reflects the complex and interactive nature of the human experience (Giddings & Grant, 2007). In the post-positivist paradigm, outcomes are observed and measured with the assumption that causative factors are interactive and acknowledgement that the human experience can be unpredictable (Creswell, 2009). Qualitative description was selected as the research strategy to reveal the lived experience of having a relative with aphasia and to describe third-party functioning and third-party disability in the terms used by the participants (Sandelowski, 2000). More detailed reporting of these findings in the context of the ICF, including mapping of specific research codes to ICF codes will be presented elsewhere.

### 4.4.2 Participants

This study was conducted in Canterbury, New Zealand and Queensland, Australia with English-speaking participants. All participants identified as being New Zealanders, Australian, and/or European with two participants from New Zealand identifying as being both Māori and European. Ethical approval was obtained from the applicable ethics committees. Individuals with aphasia nominated the family member participants. Participants with aphasia were recruited from community stroke groups and by referral from speech-language pathologists. Maximum variation sampling was used to ensure diversity within the sample of people with aphasia (Patton, 2002). Specifically, variation was sought for gender, age, years post-onset of

aphasia, severity of aphasia, and other stroke-related deficits. Severity of aphasia was informed by the score on the Western Aphasia Battery-Revised (WAB-R) (Kertesz, 2006). Individuals who scored above the aphasia cut-off score of 93.8 on the WAB-R were included if they identified as having aphasia and described aphasia-related difficulties (e.g., word-finding difficulties, impaired reading and writing, inability to follow group conversation, etc.). Total score on the Burden of Stroke Scale (BOSS) was used to measure other stroke-related deficits of mobility, self-care, cognition, swallowing, social relations, energy and sleep, and negative and positive mood (Doyle, et al., 2004). To be included in the study, people with aphasia needed to be 18 years and over and have acquired aphasia secondary to stroke. Characteristics of the 11 participants with aphasia, including gender, age, years post-onset of aphasia, aphasia quotient (the summary score derived from the WAB-R), and BOSS score (an indication of other stroke-related deficits) are displayed in table 4.1.

Participants with aphasia identified close family members using the Social Network Convoy Model (Antonucci & Akiyama, 1987). This model represents social networks through a series of concentric circles. In this case, the person with aphasia is represented in the centre of three larger circles with the innermost circle representing individuals closest to the person with aphasia, and the two outermost circles representing those who are progressively less close to the person with aphasia. Those family members named as being part of the innermost circle were approached to participate in the study. All 20 family members who were invited agreed to participate. Inclusion criteria for family members were acknowledgement that they were close to the person with aphasia and the ability to complete an in-depth semi-structured interview in English. Informed consent for participants under 18 years of age was obtained from the child/teenager themselves and their guardian after a discussion of the purpose of the study and requirements for participation. All participants were given the option to have a support person present with them during interviews. The characteristics of the family member participants are also displayed in table 4.1.

Table 4.1.

*Detailed phase 1 participant characteristics.*

| Characteristics of family members | | | | | Characteristics of people with aphasia | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| ID | Gender | Age | Relationship to PWA | Living with PWA? (If no, distance between FM's and PWA's home) | ID | Gender | Age | Number of years post-onset of aphasia | Aphasia quotient* | Burden of stroke scale score** |
| 1A | Female | 36 | Granddaughter | No (5km) | 1 | Female | 89 | 2 | 81.2 | 55.86 |
| 1B | Female | 60 | Daughter | No (5km) | | | | | | |
| 2A | Female | 79 | Wife | Yes | 2 | Male | 83 | 6 | 90.4 | 29.3 |
| 3A | Female | 51 | Wife | Yes | 3 | Male | 61 | 6 | 14.1 | 54.3 |
| 3B | Male | 17 | Son | Yes | | | | | | |
| 4A | Female | 55 | Daughter | No (5km) | 4 | Female | 85 | 40 | 77.7 | Not |
| 4B | Female | 59 | Daughter | No (10km) | | | | | | available |
| 5A | Female | 75 | Sister | No (4km) | 5 | Male | 75 | 4 | 92.7 | 55.47 |
| 5B | Male | 80 | Brother-in-law | No (4km) | | | | | | |
| 6A | Female | 65 | Sister | No (1km) | 6 | Female | 78 | 4 | 53.2 | 28.52 |
| 7A | Female | 48 | Daughter | No (15km) | 7 | Female | 88 | 5 | 58.6 | 15.23 |

| | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| 7B | Female | 62 | Daughter | No (1/2km) | | | | | | |
| 8A | Female | 80 | Wife | No (Next door) | 8 | Male | 84 | 5 | 71.1 | 24.22 |
| 9A | Male | 64 | Husband | Yes | 9 | Female | 68 | 7 | 89.7 | 47.27 |
| 10A | Female | 47 | Mother | Yes | 10 | Male | 18 | 3 | 92.4 | 12.89 |
| 10B | Male | 48 | Father | Yes | | | | | | |
| 10C | Male | 16 | Brother | Yes | | | | | | |
| 10D | Female | 15 | Sister | Yes | | | | | | |
| 11A | Female | 51 | Wife | Yes | 11 | Male | 53 | 1 | 98.6 | 25 |
| 11B | Male | 13 | Son | Yes | | | | | | |

*Aphasia Quotient= Summary score on the Western Aphasia Battery-Revised, indicating level of aphasia severity (minimum score = 0, maximum score = 100; lower scores = greater severity).

**Based on the Burden of Stroke Scale (minimum score = 0, maximum score = 100; higher scores = greater severity). This measure was used as an indication of other stroke-related deficits including mobility, self-care, cognition, swallowing, social relations, energy and sleep, and negative and positive mood.

### 4.4.3 Data collection

Data was collected through individual in-depth semi-structured interviews (Di Cicco-Bloom & Crabtree, 2006) in the participants' homes or at the university. A topic guide, with open-ended and probe questions, was used to ensure all areas of interest were covered with minimal direction from the interviewer (i.e., changes in the family member's physical health, mental health, relationships, thinking/problem solving, communication, daily routine, recreational activities, social life, domestic duties, work, education, and volunteering). Because of the lack of research into positive outcomes for family members, the interviewer specifically asked, "Have any areas of your life been affected in a positive way by having a family member with aphasia?" The interviews were digitally recorded and transcribed verbatim based on the recommendations of Poland (2001).

### 4.4.4 Data analysis

Interview transcripts were analysed according to the guidelines for qualitative content analysis set by Graneheim and Lundman (2004). First, transcripts were read to increase familiarity with the text and to gain an overarching sense of the family members' perceptions of how they have been affected by aphasia. Second, meaning units, which provided information about how family members were affected by aphasia, were identified. Third, condensed meaning units were developed by shortening meaning units to describe the essence of the family member's experience. Fourth, each condensed meaning unit was labelled with a code. Finally, similar codes were grouped into categories.

### 4.4.5 Rigour

To increase the trustworthiness of the results, this study was designed in consideration of the criteria for increasing rigour in qualitative studies including credibility, dependability, transferability, and confirmability (Lincoln & Guba, 1985). *Credibility*, or confidence in the findings, was enhanced through the use of member checks (Thomas, 2003) and peer debriefing (Lincoln & Guba, 1985). Following the interviews, 12 participants completed member checks, which allowed them to clarify or confirm the researcher's interpretation of their experience. Comments received

from participants were incorporated into the subsequent analysis. *Dependability*, the ability to replicate the data, was addressed by documenting the research process so the results may be repeated in a similar context (Glogowska, 2011). Relevance to another setting is termed *transferability* and, while it is up to the reader to judge, transferability in this study has been facilitated by a thorough description of the context, participants, data collection, and analysis (Mertens, 2010).

Within the post-positivist paradigm, it is acknowledged that the researcher is not completely objective, bringing their own experiences and biases to the research, which may influence the results (Sandelowski & Barroso, 2002). *Confirmability* is the extent to which the findings come from the participants and not the researchers' bias. Two potential biases in this study are the influence of the ICF (i.e., this research is based on the framework of the ICF and the authors previously conducted two systematic reviews based on the ICF) and the authors' experience as speech-language pathologists working with people with aphasia and their family members. To address these sources of bias, the primary investigator kept detailed notes throughout the research period, particularly around interviews, to document reflections, observations, and experiences (Carlson, 2010). Notes were consulted during data collection and considered in the initial phases of data analysis. Furthermore, the authors addressed these issues by examining the analysis in the context of these biases, particularly the influence of the ICF, and by ensuring that the codes and categories were identified inductively from the participants' data.

## 4.5 RESULTS

### 4.5.1 Positive aphasia-related changes associated with third-party functioning in family members of individuals with aphasia

Sixteen family members reported at least one positive effect of aphasia; conversely, two family members felt strongly that there are no positive effects of having a relative with aphasia, *"Nothing positive comes from aphasia"* (ID-10A). Five categories of positive aphasia-related changes associated with third-party functioning were revealed through analysis of the data: (1) emotions; (2)

communication; (3) relationships; (4) recreational activities and social life; and (5) paid/volunteer work or education. These categories are described below.

### *1. Emotions*

***"****I've learnt to appreciate a lot more… that's a good thing"* (ID-10B).

Many family members experienced positive emotions secondary to aphasia. For example, some felt proud of themselves and the person with aphasia for overcoming difficulties associated with aphasia, *"I know she must feel… quite isolated because of her inability to carry through a conversation. And… I'm really proud of her, how much she tries actually. She still picks up the phone and calls people"* (ID-1A). Others found that aphasia made them more appreciative and hopeful, "*...we probably appreciate each other more and… think how lucky we are… you probably don't think that until something goes wrong"* (ID-2A). And, "*I think the biggest thing with aphasia for me is… finding hope. You know… finding young people who've successfully overcome aphasia"* (ID-10A). Sometimes aphasia meant that family members developed a more positive outlook and even laughed more often, *"Through bad things, you know difficult things, good things come as well and we, we try and look at the good stuff…"* (ID-10B). And, "*We have some laughs… and she laughs, because she knows she's fired the wrong one out*" (ID-1B).

### *2. Communication*

*"We probably talk more… I learnt more about* [husband with aphasia] *and how he was feeling, than I had in the past…"* (ID-11A).

Family members described positive changes to the way they communicate with their relative with aphasia and the content of that communication. Several family members reported talking to their relative with aphasia more openly and frequently. One family member felt it was positive that since the onset of aphasia, she and her husband talked more about their health.

### *3. Relationships*

*"All* [of] *our relationships have become stronger with family members…"* (ID-10D).

Family members reported positive changes to their relationship with the person with aphasia, as well as with other relatives. They also valued new relationships that were formed as a consequence of aphasia and reported changes in their attitudes towards others. Many family members reported feeling closer to the person with aphasia and often did special things for them. One family member and her long-term partner married after the onset of his stroke and aphasia. Non-spouse family members reported an increase in physical affection, *"I touch him all the time. Put my arm round him, kiss him, hug him… and I* [have] *probably gone and done it even more, since his aphasia"* (ID-10B). Several family members reported that they were happy to spend extra time with the person with aphasia following the stroke.

Participants reported that their family worked together better, spent more time together, and became closer. Some even felt closer to their extended family when aunts and uncles, cousins, and grandparents became more involved. Siblings of people with aphasia suggested that aphasia had the effect of bringing the family closer together. Children of participants with aphasia discussed how aphasia influenced their relationship with both their parents. Two reported being closer to both parents; however, others felt they became closer to the parent without the aphasia through working together and talking more.

Many family members reported being happy to have met wonderful people they would not otherwise have met (i.e., other people with aphasia, their family members, and health professionals) and becoming more tolerant of others, particularly those with disabilities. *"...* [aphasia has] *made us think a little bit more about the fact that… these things can happen to people. Anybody, anywhere, anytime"* (ID-7A).

***4. Recreational activities and social life***

*"I think now, what might* [person with aphasia] *be doing this weekend or what might she want to do or… how can I include her?"* (ID-7B).

Family members replaced former recreational activities with new ones that they could do with their relative with aphasia and often reported enjoying the new activities. *"I could go back to doing some things, but we like doing things together… it's worked out well really"* (ID-2A). Changes in socializing occurred when family members became a source of social contact for their relative with aphasia and/or participated in social activities with them. "*Her aphasia is one of the key reasons that's made it more important for me to make sure that I visit frequently cause she needs that social contact"* (ID-1A).

***5. Paid/volunteer work or education***

*"… I've learnt a whole lot about, a whole new field I knew nothing about"* (ID-9A).

Family members described professional development as a consequence of their relative's aphasia, specifically those working as doctors, nurses, or speech-language pathologists. *"I thought I was empathic… but I'm a lot more empathic than I was because you know I tend to see things from the other side"* (ID-10B). Two family members altered their educational career path to include aphasia. Others began volunteering in the areas of brain injury, caregiving, and/or aphasia.

Most family members reported learning more about aphasia, communication, the healthcare system, and/or caregiving through participation in their relative's rehabilitation or through self-directed research. Many family members read books and looked up material on-line, while others arranged appointments for discussions with medical professionals.

Table 4.2 displays the categories of positive changes experienced by family members as a consequence of aphasia, which are associated with improved Functioning or third-party functioning. The table lists the research category generated from qualitative interviews, the number of family members reporting a change within this category, a sample research code generated from family members' reports, the classification of the family member report according to the appropriate component of Functioning and Disability from the ICF, and the corresponding ICF domain.

Table 4.2.

*Positive aphasia-related changes associated with third-party functioning*.

| **Research category** | **Number (%) of family members reporting a change in this category** | **Sample research code** | **Associated component of Functioning and Disability** | **Corresponding ICF domain** |
|---|---|---|---|---|
| Emotions | 11 (55%) | Appreciation | Body Functions | Mental Functions |
| Communication | 3 (15%) | Change in content of communication with PWA | Activities and Participation | Communication |
| Relationships | 13 (65%) | Family is closer | | Interpersonal Interactions and Relationships |
| Recreational activities and social life | 4 (20%) | Met new people | | Interpersonal Interactions and Relationships |
| Paid/volunteer | 5 (25%) | Professional development | | Major Life Areas |

work or education

PWA = person with aphasia

### 4.5.2 Negative aphasia-related changes associated with third-party disability in family members of individuals with aphasia

All twenty family members described at least one negative of effect of aphasia. The data analysis revealed seven categories that described the negative effects of aphasia on family members associated with third-party disability: (1) physical, mental, and emotional health; (2) communication; (3) relationships; (4) recreational activities and social life; (5) paid/volunteer work or education; (6) domestic and caregiving responsibilities; and (7) finances. Each of these categories is described below.

***1. Physical, mental, and emotional health***

*"Stress and worry… really do affect your mental health"* (ID-10A).

Family members described negative changes to their physical body including difficulty sleeping and changes in sleeping patterns, less energy, weight loss/gain, and poor diet. One family member explained her feeling of exhaustion while her mother with aphasia was in hospital, *"I mean you're with this person who used to be so independent and suddenly, you're the one who's trying to do everything for them. Be their voice, be their, you know, caregiver when you're with them. And, it's very draining"* (ID-7B).

The onset or recurrence of certain health conditions were also associated with aphasia, such as depression, vertigo, ulcer, hypertension, and anxiety. One family member explained that aphasia triggered her pre-existing depression and another described increased anxiety, *"… I was in an absolutely dreadful state. My anxiety levels were huge and, um,* [my mother with aphasia] *was unable to explain…"* (ID-7B). The spouse of a woman with aphasia said he takes medication to *"calm me down"* (ID-9A) as a consequence of aphasia. Children did not report changes in their health or physical functioning as a consequence of aphasia.

Family members described negative changes to their mental functioning. They expressed difficulty focusing, remembering, and feelings of being stressed and pressured. *"I'm distracted a lot… focus is really hard… and I think the stress and the worry about aphasia and communication stuff… I find it can render me a bit functionless"* (ID-10A).

Family members experienced negative emotions secondary to aphasia, such as being more emotional or sensitive. *"When you have a person with aphasia in the family and that's put a… lot of emotional load on us"* (ID-10B). Family members were shocked by the stroke and sudden onset of aphasia. Initial worry about their relative's survival became concern about how their relative would cope with aphasia and other stroke-related disabilities over time. Many family members said they experienced long-standing guilt, grief, and sadness associated with aphasia. *"Guilt… because I was there… with him when he was having it* [the stroke]. *I just didn't recognise he was having one so I could have easily cut another, thirty minutes out, which could have stopped so much more of his brain dying"* (ID-10C). Difficulty communicating caused many family members to feel frustrated and irritated, *"I get a bit frustrated with her when she gets stuck and she can't find the word and then we get into a guessing game"* (ID-1A). Two family members felt lonely or that they had no one to talk to.

**2. *Communication***

*"I think having the aphasia has meant that we've had to… find perhaps new ways of… communicating"* (ID-3A).

The majority of family members identified changes in their communication with the person with aphasia. They also described assisting the person with aphasia to communicate with other relatives, friends, and people in the community and speaking on their behalf. Difficulty communicating meant that the content of discussions between family members and the person with aphasia became less complicated, *"You*

*can't… have deep and meaningful conversations*" (ID-7A). The types of conversations also changed as family members and people with aphasia were often unable to discuss or argue as they had previously, *"... Pre-aphasia… we could discuss it… in in ten minutes and come up with a… decision. But… that doesn't happen anymore"* (ID-9A). This often meant that family members either took sole responsibility for decision-making or persevered to ensure that the person with aphasia understood and was able to fully participate in complicated decisions. *"It can… be time consuming… real frustration sometimes… because it's… not always abundantly clear to* [the person with aphasia] *what the options are, and you know gotta go through them, patiently, so that* [the person with aphasia] *can understand them and you know is happy with whatever decision"* (ID-9A).

Family members learned to communicate in a new way to better comprehend their relative and to be better understood through interpreting, using gestures, and giving the person with aphasia extra time to speak. They also used these strategies while supporting their relative to communicate with others. *"Everyone sometimes got annoyed because they would try and have a conversation but it would be too hard for* [the person with aphasia]. *So instead we had to do it really short with simple words. And you always had to talk directly to him. And very loudly… and then you had to be quiet for awhile while he got his words together"* (ID-10D). Family members helped the person with aphasia to communicate with friends, other relatives, and people in the community such as medical professionals, sales people, teachers, lawyers, and contacts for potential employment. *"I'd go to the bank… I'd just go in and just sort of stand back… And if he couldn't get the message quite across just sort of chip in and say, well, he wants to transfer or something like that"* (ID-4B). Family members frequently made phone calls for the person with aphasia.

### 3. Relationships

*"…the relationship that's changed"* (ID-11A).

The nature of the relationship between the family member and the person with aphasia often changed significantly after the onset of aphasia. As the person with aphasia became more dependent and their needs became a priority, many family members explained that they became a caregiver. In many cases, this meant that family members spent more time with the person with aphasia, often also becoming a main source of social contact for them. Some perceived the extra time spent with their relative with aphasia to be a burden. In most cases, shared activities were also affected by aphasia, *"We used to kick a ball around and that…we don't do that as much anymore. Cause… he has to try harder to talk and communicate"* (ID-11B).

Many family members said that they did not feel as close to the person with aphasia or get along with them as well as they had prior to the stroke due to communication changes. Some family members also described keeping secrets from them. Others felt they missed out; one blamed aphasia when her parents were unable to attend her wedding, and another conveyed disappointment that her mother could not be the kind of grandparent she had hoped that she would be. *"I'd always had this idea of being able to have the children's grandparents to look after… the children, and… to be part of it"* (ID-4B). Family members whose spouses had aphasia reported less frequent sexual intimacy, though this was often replaced by other forms of physical intimacy.

Family members also experienced negative changes to their relationships with other relatives and friends. Children of people with aphasia described taking over the role of the adult or looking to a different person to act as their parent instead of the person with aphasia. Siblings of people with aphasia reported an overall change to the family and how it generally functioned. When the siblings were still living at home with their parents, they reported changes in their relationships with their parents. Some said they were given more freedom and independence, while others found their parents to be more protective of them.

Parents of those with aphasia described how their relationship with other children in the family changed as they focused on the well-being of their child with

aphasia. They noted that the combination of increased expectations for the healthy children, and extra patience directed towards their child with aphasia, created tension in their relationships with other children. Parents talked about an increased need to support their spouse to maximize the outcome for their child with aphasia and to minimize the negative effects experienced by their spouse due to increased duties and stress. The mother of a teenager with aphasia said, *"… I think we're* [family member and her husband] *really aware of each other's… emotional needs and frailties with worrying about the aphasia"* (ID-10A). Some participants noted that contact with extended family was reduced.

Aphasia impacted family members' relationships with their friends in negative ways. Many family members described spending less time with their friends, having fewer friends, and becoming less close to them. Some said they had less time for them, while others felt their friends could not understand aphasia, *"The sympathy bucket is empty"* (ID-10A). Changes in relationships with friends also influenced social activities, as reported below.

**4. Recreational activities and social life**

*"When you've spent quite a lot of your week trying to communicate… you don't actually want to go out and make small talk with people"* (ID-7A).

Family members experienced mostly negative changes to their recreational activities and social life. Many found they were often too busy to relax on a day-to-day basis and took fewer vacations. One family member explained that she used up her allocated sick leave at work to take care of her mother with aphasia and needed to use some of her paid holiday time as well. *"The amount of times I've had to take off work, take a day's leave. It's not for holiday… it's a day's leave because she needs something"* (ID-1B).

Almost all family members experienced changes to their leisure activities, hobbies, and sports. Generally, the more dependent their relative with aphasia was,

the less time and energy family members had for independent activities they used to enjoy. Though family members found new activities and hobbies, they missed the ones they used to do (e.g., playing a team sport with the person with aphasia instead of swimming). Family members reported going out less often and participating in fewer social activities. Some had less desire to socialize or preferred to spend time with family over friends.

**5. Paid/volunteer work or education**

*"You can get a bit obsessed about the old aphasia… trying to find information and trying to connect with people… it's a bit consuming"* (ID-10A).

Family members frequently reported changes to their work, volunteering, and education. Due to the increased responsibility related to aphasia, many worked fewer hours or took extended time away from work, at least for a short time post-stroke. Some resigned from their jobs or changed their work schedule to be available for supporting the person with aphasia. Family members who volunteered in some capacity prior to the onset of their relative's aphasia stopped volunteering. Two children felt their grades in school had dropped secondary to aphasia.

***6. Domestic and caregiving responsibilities***

*"I've had to take it all on really"* (ID-3A).

Family members discussed increased responsibilities associated with household duties and in providing care to their relative with aphasia. They reported taking on more household chores, essentially doing what the person with aphasia used to do, or covering for other family members who were directly supporting the person with aphasia, in addition to their own responsibilities, *"You're… doing twice as much* [housework]… *as well as looking after somebody"* (ID-2A). These activities included arranging for maintenance of the person with aphasia's home, helping the person with aphasia to understand legal decisions, managing the person with aphasia's finances, organising insurance, completing stroke-related paperwork, and

running errands with the person with aphasia (e.g., shopping, bank, pharmacy, medical appointments, etc.)

Family members also reported an increase in caregiving duties such as monitoring the person with aphasia's health, overseeing medical and personal care, navigating the medical system, organizing their day, monitoring their behaviour, supporting the person with aphasia's social interactions, and visiting them. *"It's all I did all day was to manage his* [the person with aphasia's] *care"* (ID-11A). Many family members actively supported the person with aphasia to participate in speech therapy by driving them to appointments, participating in sessions, and following up with homework. Some family members developed their own materials and actively involved the person with aphasia in communication tasks, *"I'm like his speech therapy all the time… I try and get him talking…"* (ID-10C). The need to explain aphasia to others was also commonly reported by participants who sometimes described aphasia to store clerks, their extended family, and friends informally, or volunteered for formal presentations about aphasia such as with medical professionals, *"I often say, she's not deaf and she's not stupid, she just has difficulty talking"* (ID-1B).

In some cases, family members also described becoming the caregiver to another relative as a consequence of the aphasia. The daughter of a woman with aphasia noted how she looked out for both her parents and said, *"We were aware of… watching Dad* [husband of the person with aphasia] *cause often the person you're focused on isn't the person… that ends up going first… everyone's focused on the sick person"* (ID-4B). Other family members shared how they needed to support the family member who had taken on the majority of the responsibility associated with aphasia, *"My main concern is not with* [the person with aphasia], *it's with* [my wife]… *because… she struggles with it… she does a fantastic effort but she just wears it so heavily…"* (ID-10B).

**7. Finances**

*"Financially, I feel that it probably did have an effect on us…"* (ID-4B).

Family members reported that aphasia had a negative impact on their finances, resulting from reduced work hours associated with the support they provided to their relative with aphasia. *"It meant the income drop…"* (ID-1A). This meant less spending money and a change in their financial position. Family members also indicated an increase in petrol costs due to transporting the person with aphasia places.

Table 4.3 shows the research categories that include negative family member reports associated with Disability, or third-party disability. In addition, the number of family members who reported a change in the category, a sample research code generated from family members' reports, and the classification of the family member report according to the appropriate ICF component, and ICF domain are displayed.

Generally, the positive and negative effects of aphasia on family members evolved over time. Family members explained that they were initially focused on coping with the sudden change in their relative's health and functioning and later began to deal with the ongoing implications of aphasia. It was not until the person with aphasia returned home that family members began to experience more extensive changes to their lives, *"It's different now than it was in the beginning. In the beginning… it was really hard because… it's such a shock to you, the aphasia part cause you are trying to figure out how to manage it. Well I didn't know what aphasia was… and … now my life is still not normal"* (ID-10A).

Table 4.3.

*Negative aphasia-related changes associated with third-party disability*.

| **Research category** | **Number (%) of family members reporting a change in this category** | **Sample research code** | **Associated component of Functioning and Disability** | **Corresponding ICF domain** |
|---|---|---|---|---|
| Physical, mental, and emotional health* | 17 (85%) | Fatigue<br>Guilt | Impairments | Mental Functions |
| Communication | 17 (85%) | Difficulty conversing with PWA | Activity Limitations and Participation Restrictions | Communication |
| Relationships | 19 (95%) | Not as close to PWA | | Interpersonal Interactions and Relationships |
| Recreational activities and social life | 14 (70%) | Fewer social activities | | Community, Social and Civic life |

| | | | |
|---|---|---|---|
| Paid/volunteer work or education | 10 (50%) | Quit job | Major Life Areas |
| Domestic and caregiving responsibilities | 18 (90%) | Increased household chores | Domestic Life |
| Finances | 6 (30%) | Less spending money | Major Life Areas |

PWA = person with aphasia

*Note that this within this category, some family member reports were considered health conditions (e.g., depression), which are classified outside the scope of the ICF.

## 4.6 DISCUSSION

This investigation uniquely demonstrates how the standardized language and framework of the ICF can be used to conceptualise changes in Functioning and Disability experienced by family members of people with aphasia. Positive outcomes attributed to aphasia are related to improved Functioning, or third-party functioning, and consist of Body Functions, Activities, and Participation. Negative family member reports were classified as Impairments, Activity Limitations, and Participation Restrictions, which contribute to the development of Disability, or third-party disability.

In addressing the first aim of this study, the current study adds to the literature by identifying five categories of positive effects of having a relative with aphasia, associated with third-party functioning. Of the few positive outcomes for family members reported in previous studies, those also described in this study included hopefulness and appreciation (Pringle, Hendry, McLafferty, & Drummond, 2010), improved relationship with their spouse (Williams, 1993), improved relationships other family members (King & Shade-Zeldow, 1995), and meeting new people (Nätterlund, 2009). Family members also discussed personal growth associated with their experience of aphasia (Nätterlund, 2009) and more instances of physical affection between the family member and the person with aphasia, although, in the cases of spouses of people with aphasia, sexual contact was often diminished (Lemieux, Cohen-Schneider, & Holzapfel, 2001; Michallet, et al., 2003). While reported in one prior study (Malone, Ptacek, & Malone, 1970), the positive findings of increased participation in social activities with friends (i.e., entertaining and visiting) and taking more vacations were not reported in the current study. No positive effects of aphasia were reported related to domestic and caregiving responsibilities and finances.

In addressing the second aim of this study, the results show that aphasia has pervasive negative effects on the lives of family members, associated with third-party disability, as revealed in the seven categories generated. Many of the negative effects

of aphasia reported here have been found in previous studies, so of particular significance is the replication of detailed findings that have been reported by only a small number of studies with methodological limitations or few participants. For example, this study corroborates previous findings that family members feel a sense of loss of control (Christensen & Anderson, 1989), irritation (Christensen & Anderson, 1989), effort to maintain emotional balance (King & Shade-Zeldow, 1985), and changes to their sleeping and eating habits (Artes & Hoops, 1976). Further support was also provided to family members' reports of having fewer discussions with the person with aphasia (Gillespie, Murphy, Place, 2010), withdrawal from social situations (Malone, Ptacek, & Malone, 1970), moving from full to part-time employment (Salonen, 1995), and resigning from a volunteer position (Denman, 1998).

The Activity Limitations and Participation Restrictions identified in this study are similar to the handicaps revealed in relation to the ICIDH in the study by Le Dorze and Brassard (1995). These include changes in emotions, communication, the relationship between the person with aphasia and the family member, friendships, recreation and social involvement, career and education, and household and caregiving responsibilities. In comparison, the current study reveals additional changes to health, finances, and the need to support other relatives who are affected by aphasia.

These findings provide an overview of third-party functioning and third-party disability in aphasia with implications for the provision of family-centred care. The research categories generated are indicative of the effects of aphasia on family members at various stages post-stroke that clinicians may consider when developing rehabilitation goals and making appropriate referrals (Howe et al., 2012). Changes to family members' Functioning should be considered in intervention planning as positive outcomes of aphasia may have the effect of mitigating the negative consequences (Rapp & Chao, 2000; Toljamo, et al., 2012). Confirmation that the impact of aphasia goes beyond spouses and primary caregivers provides further evidence for the inclusion children and other relatives in family-centred care (Howe et al., 2012). In addition, the need for ongoing assessment of family members and supporting them over time is highlighted (Le Dorze & Signori, 2010; Nätterlund, 2009). The results also provide a possible explanation for the more significant

problems experienced by family members caring for people with aphasia compared to those caring for relatives without aphasia post-stroke (Bakas, et al., 2006). Specifically, this study shows that providing care to someone with aphasia involves helping them to communicate, being an active part of their social life, assisting them with financial and legal matters, and educating others about aphasia, in addition to the duties typically associated with caregiving (e.g., transportation, household management, physical care, etc.) These different responsibilities associated with caring for and interacting with someone with aphasia may mean that there are different rehabilitation goals for family members of people with aphasia than for family members of those with other health conditions.

Use of the internationally recognized ICF to provide a framework for these findings may facilitate the development of policy that is more inclusive of family members and support funding for family-centred care. Understanding how aphasia impacts upon a family member's Functioning and Disability from the perspective of the ICF also highlights the possibility of preventing the development of a health condition, or lessening its effects. As the ICF shows, there is a dynamic interaction between Functioning and Disability, Contextual Factors, and the health condition. Through this mutual influence, Disability that occurs as a consequence of a significant other's aphasia can lead to the development of a health condition. Consequently, appropriate early intervention in response to changes in family members' Functioning and Disability are vital for the prevention of associated health conditions.

The development or worsening of a health condition can be an significant consequence of aphasia for family members as it may be associated with further Impairments, Activity Limitations, and Participation Restrictions. Participants in this study reported exacerbation of existing health conditions, including anxiety, depression, ulcer, vertigo, and hypertension. Anxiety and depression were noted by two family members as occurring since and as a consequence of aphasia. Other studies have shown that family members of people with aphasia experience a high rate of depression (Bakas, et al., 2006; Hemsley & Code, 1996; King & Shade-Zeldow, 1995; Kinsella & Duffy, 1978; McGurk, et al., 2011; Wade, et al., 1986). Anxiety has been less commonly explored in family members of people with stroke, even though anxiety may be more prevalent than depression in this population (Greenwood & Mackenzie, 2010) and burden, anxiety, and depression are related

(Visser-Meily, et al., 2009). A comprehensive investigation of anxiety in family members of people with aphasia has not been conducted, though anxiety in family members has been identified in other studies (Hemsley & Code, 1996; Le Dorze, et al., 2009; Michallet, et al., 2003; Nätterlund, 2009; Pound, et al., 2001; Rice, et al., 1987). Given the incidence of depression and anxiety in family members and the association between the two, clinicians should be alert to these conditions (Visser-Meily et al., 2009). In addition, family-centred interventions should include measurement of anxiety and depression in family members.

### 4.6.1 Strengths and limitations

A key strength of this study was the specific investigation into the positive effects of aphasia on family members, providing a better understanding of participants' complete experience. Another strength of this study was the diversity of participants; specifically, minor children and siblings of people with aphasia, male family members, and multiple close family members from the same family who together provided a broad picture of the ways that aphasia can impact upon different family members. Future research may address the limitations of this study. First, as this was a qualitative study and measures were taken to improve transferability of the findings, the results are not considered to be generalisable to the population of family members of people with aphasia. Generalisation will occur in the second phase of this study through a larger survey of family members of people with aphasia, currently underway. Second, this research relied on the participants' recollection of their experience with aphasia over time rather than following participants longitudinally. Future longitudinal studies will help to better understand the progression of third-party disability. In addition, subsequent studies may investigate the influence of specific Environmental Factors and/or Personal Factors on third-party functioning and third-party disability (e.g., religious beliefs, social support, nature of the relationship between the person with aphasia and their family member before the stroke).

Another consideration related to the nature of this research is the issue of attributing changes in Functioning and Disability to the aphasia and not other aspects of the stroke or other areas of life. As one family member said, *"...it's not only the*

*aphasia, of course, it's the whole stroke…"* (ID-10B). While family members were aware of the definition of aphasia and that the aim of this research was to determine how aphasia affected them, it was not always relevant for them to isolate the impact of aphasia. Therefore, in the interviews, family members sometimes talked about the experience of their relative's stroke as a whole. Thus, these results revealed the complex lived experience of family members of people with aphasia due to stroke (Barrow, 2008; Le Dorze & Signori, 2010; Michallet, et al., 2003). In future studies, a comparison of the experiences of family members of people with and without aphasia post-stroke, may increase knowledge of the unique impact of aphasia versus other types of stroke-related difficulties.

## 4.7 CONCLUSION

This study provides further evidence of the extensive effects of aphasia on family members confirming that aphasia is indeed a family problem. Considered within the framework of the ICF, the results show how aphasia can impact on family members' Functioning and Disability. Positive consequences of aphasia may contribute to improved Functioning related to Body Functions, Activities, and Participation; in their negative form, these changes are associated with Impairments, Activity Limitations, and Participation Restrictions. Thus, family member participants have described their experience of third-party functioning and/or third-party disability secondary to aphasia. Understanding outcomes for family members as changes in Functioning and Disability may lead to the appropriate inclusion of family members in rehabilitation as a matter of policy and provides an overview of areas that likely require clinical support to minimize or prevent third-party disability.

# CHAPTER 5

## USE OF THE ICF TO DESCRIBE THE IMPACT OF APHASIA ON CLOSE FAMILY MEMBERS[4]

**Grawburg, M., Howe, T., Worrall, L., & Scarinci, N. (2013). Describing the impact of aphasia on close family members using the ICF framework. *Disability and Rehabilitation*. Advance online publication. doi: 10.3109/09638288.2013.834984**

[4]This chapter is an adaptation of the manuscript, entitled "Describing the impact of aphasia on close family members using the ICF framework" published in Disability and Rehabilitation in 2013. It is inserted as submitted with modifications to the text to ensure consistency and relevance to the current chapter and thesis.

## 5.1 ABSTRACT

Background: The previous chapter revealed that aphasia has positive and negative effects on family members' lives. Despite these findings and other existing literature demonstrating the pervasive and significant effects of aphasia on family members, rehabilitation programming, policy, and funding are not well developed.

Purpose: The aim of this qualitative study was to describe the impact of aphasia on family members in the context of changes to their Functioning and Disability using the framework of the International Classification of Functioning, Disability and Health (ICF). Application of ICF concept of disability or 'third-party disability' to family members of people with a health condition is discussed.

Method: Twenty family members participated in individual in-depth semi-structured interviews. Interviews were analysed using qualitative content analysis. Research codes generated were subsequently mapped to the ICF.

Results: The results of this study showed that family members experienced positive, neutral, and/or negative changes to their Body Functions and Activities and Participation due to their significant other's aphasia. Moreover, some family members attributed the development of a health condition or exacerbation of an existing health condition to the aphasia.

Conclusion: Interpreted within the framework of the ICF, the results of this qualitative study reveal that family members of people with aphasia experience changes to their functioning and disability, known as 'third-party functioning and disability', as a consequence of the health condition of a significant other.

## 5.2 INTRODUCTION

The impact of an individual's health condition on their family members is a current issue for policy, research, and rehabilitation. This issue is particularly relevant in the field of communication disorders where the two-way nature of communication has a direct effect on family members through their interactions, relationship, and shared environment with the person with the disorder. Stroke or other injury may cause damage to the language areas of the brain and result in aphasia. Aphasia is a communication disorder associated with impairments in spoken language, understanding, reading, and writing, which affect an individual's ability to perform daily activities and participate in society. Studies have shown that aphasia has pervasive effects on family members, including the development of depression and other minor psychiatric disorders (Grawburg, et al. 2013a, 2013b). In addition, family members of people with aphasia take on caregiving duties (Bakas, et al., 2006; Le Dorze & Signori, 2010) and the responsibility of helping the person with aphasia communicate (Gillespie, et al., 2010; Le Dorze & Signori, 2010) as well as experiencing changes to their own social and recreational activities (Herrmann, et al., 1995; Kinsella & Duffy, 1979; Le Dorze & Signori, 2010) and their relationships with others (Gillespie, et al., 2010; Michallet, et al., 2003).

Given the considerable consequences of a significant other's health condition on family members, it has been suggested that they be considered in rehabilitation, not just as supporters of the person with the condition, but as individuals with their own needs for rehabilitation (Visser-Meily et al., 2006; WHO, 2011). In a family-centred care model, family members are included as clients in all phases of the rehabilitation process in order to address their concerns associated with the health condition of their significant other (Visser-Meily et al., 2006). Family-centred care acknowledges that the family members' well-being influences the person with the health condition, thus family members' needs and expertise are an integral part of goal-setting and decision making (Hughes, Bamford, & May, 2008; Visser-Meily et al., 2006). Despite the extensive literature reporting the effects of aphasia on family members, family-centred rehabilitation programs, policy, and funding are not well established (Johansson, et al., 2011; Law, et al., 2010; Levack, et al., 2009; Sherratt et al., 2011). This could be due to a lack of consistency in the description of outcomes

for family members, which have included poorly defined terminology such as caregiver burden and quality of life (Greenwood, et al., 2008).

The ICF provides a common structure and vocabulary for conceptualising health and disability (WHO, 2001). It defines components of health and health-related states to allow users to describe an individual's functioning and disability as part of a dynamic interaction between the health condition and contextual factors. The ICF is composed of two parts. The first part, *functioning and disability*, includes the components of i) Body Functions and Body Structures and ii) Activities and Participation. Functioning represents the neutral or positive aspects of Body Functions, Activities, and Participation, while disability is described in terms of impairments to Body Functions and Structures, Activity Limitations, and Participation Restrictions. For example, a person with aphasia may experience Impairments such as anomia or auditory processing difficulties, Activity Limitations like difficulty speaking on the telephone, and Participation Restrictions such as being unable to continue in their job. Aphasia is also associated with Activity Limitations and Participation Restrictions in ICF domains besides communication such as general tasks and demands, self-care, domestic life, and interpersonal interactions and relationships (Simmons-Mackie & Kagan, 2007). The second part of the ICF, Contextual Factors, includes Environmental Factors and Personal Factors. Environmental Factors include the physical environment and social systems, as well as the attitudes of and relationships with other people. Personal Factors include aspects such as lifestyle, habits, and coping styles, but are not currently classified by the ICF.

As an internationally recognized framework for conceptualising health and disability with a common vocabulary, the ICF may provide an appropriate structure for understanding the effects of aphasia on family members (Threats, 2010). Like other models of disability, such as the Institute of Medicine model (Pope & Tarlov, 1991) and the National Center for Medical Rehabilitation Research model (National Center for Medical Rehabilitation Research, 1993), the ICF describes the role of the environment in the development of disability. However, the Quebec Classification (Fougeyrollas, et al., 1999) is the only model that explicitly accounts for the influence of a significant other's health condition on family members through its Disability

Creation Process. In the ICF, the WHO introduced the term *"third-party disability"* and indicated a need for further research into the *"... disability and functioning of family members ... due to the health condition of a significant other"* (WHO, 2001, p. 251). Subsequently, Scarinci and colleagues (2009) developed a model based on the ICF, to explain 'third-party disability' in spouses of older people with hearing impairment. The model shows how the hearing impaired partner's functioning and disability act as an environmental factor influencing the spouse's functioning and disability. As the ICF is the most widely accepted model of disability (Masala & Petretto, 2008), we have elected to use the ICF framework and the term 'third-party disability' to describe the disability experienced by family members of people with aphasia to ensure differentiation between *disability* (i.e., as a result of the interaction between contextual factors and individual's health condition) and *'third-party disability'* (i.e., a change in functioning and disability resulting from the environmental factor of a significant other's health condition). The term '*third-party functioning'* is used to encompass the range of positive and neutral changes experienced by family members (Grawburg, et al., 2012; Grawburg, Howe, Worrall, & Scarinci, 2013b).

Traditionally, the ICF has been used to describe the health and health-related states of individuals with a health condition. So while the ICF would certainly be used to classify a family member's stress-related health condition (i.e., clinical depression secondary to a significant other's aphasia), use of the term 'disability' or 'third-party disability' to describe the effects of the health condition of a significant other on the functioning and disability of a close family member who does not have the condition may be considered controversial. However, there are a number of reasons why use of the term 'third-party disability' is appropriate for investigating the impact of health conditions, such as aphasia, on close family members.

First, changes to family members' functioning and disability that can be attributed to the health condition of a significant other are health outcomes and therefore fit within the scope of the ICF. In particular, family members would not experience these changes to Functioning and Disability (i.e., Impairments, Activity Limitations, and Participation Restrictions) if it were not for their significant other's health condition. As a framework for the "description of health and health-related states" (WHO, 2001, p. 3), the ICF explains how disability can result from a

significant other's health condition (Threats, 2010). The ICF specifically states that investigation into 'third-party disability' should involve the "study of disability and functioning" (WHO, 2001, p. 251) and not necessarily changes in a family members *health condition*. In addition, WHO has recognized the importance of this concept in research and clinical practice through its inclusion of 'third-party disability' in the ICF (Threats, 2010; WHO, 2001).

Second, use of the ICF to describe 'third-party disability' is consistent with the underlying ICF principle of universality, "*There is a widely held misunderstanding that ICF is only about people with disabilities; in fact, it is about all people. The health and health-related states associated with all health conditions can be described using ICF. In other words, ICF has universal application."* (WHO, 2001, p. 7). Furthermore, the ICF includes cases of its application to people without an impairment or health condition (WHO, 2001). For example, a man who is regularly tested for HIV as part of his job working with people with AIDS faces Participation Restrictions in the 'community, social and civic life' domain of the ICF due to negative attitudes by people in his environment. A second example describes a woman who carries a genetic code that puts her at increased risk for breast cancer. Despite not having a health condition, she faces Participation Restrictions related to the ICF domain of 'looking after one's health' as she has difficulty obtaining health insurance.

Third, recognition of the concept of 'third-party disability' allows health systems to address the needs of family members. Use of the term supports the ICF aim of establishing *"...a common language for describing health and health-related states in order to improve communication between different users, such as health workers, researchers, policy-makers and the public, including people with disabilities..."* (WHO, 2001, p. 5) as it provides a framework for describing the impact of a health condition on those affected, including the person with the health condition and their close family members, promoting a system that facilitates family-centred care. As the ICF is intended to set the standard for modelling social policy, it is appropriate that family member data be included within its scope, especially as there is an increasing emphasis on community care, often with family members in informal support roles (WHO, 2011). With this in mind, classification of 'third-party disability' according to the common language of the ICF may facilitate improvements

in policies and services related to family-centred care. Family members may be seen by health professionals for assessment of their health status, counselling, participation in support groups, rehabilitation, and monitoring of physical, mental health, and family functioning (Visser-Meily, et al., 2006). Thus, 'third-party disability' can be seen to represent domains of health that *"...for health systems purposes, can be defined as the primary responsibility of the health system."* (WHO, 2001, p. 212), placing the consequences of the health condition of a significant other on family members within the scope of the ICF (WHO, 2001). Improved care for family members may also have related positive implications for the person with the health condition.

Finally, we suggest that use of the ICF to describe 'third-party disability' is appropriate within the context of health, particularly given the history of the concept. Though the term 'third-party disability' has entered the literature quite recently, previous research has used the terminology of the precursor to the ICF, the International Classification of Impairments, Disabilities and Handicaps (ICIDH) (WHO, 1980), to discuss 'handicaps' experienced by family members of people with aphasia and hearing impairment. Stephens and Hétu (1991) proposed an extension to the notion of handicap as described in the ICIDH to include the influence of a health condition on family members. Since then, other reports have indicated that family members with normal hearing can experience "handicapping and/or disabling situations" as a consequence of their significant others' hearing loss, though they do not have the condition themselves (Gagné, 1998; Gagné, Hétu, Getty, & McDuff, 1995; Hétu, Riverin, Lalande, Getty, & St-Cyr, 1988). Similarly, Le Dorze and Brassard (1995) classified the consequences of aphasia for family members according to the ICIDH category of handicaps revealing that family members experienced handicaps related to their communication situation, interpersonal relationships, responsibilities, and participation in work and leisure activities.

Moreover, publications that have applied the concept of 'third-party disability' in the fields of neurogenic communication disorders and audiology set a precedent for understanding the impact of a significant other's health condition on family members within an established framework of health and disability (Grawburg, et al., 2012, 2013a, 2013b; Scarinci, et al., 2009, 2011, 2012). A study in the field of hearing impairment showed that spouses experienced 'third-party disability' secondary to

their partner's hearing impairment with implications for the ICF domains of communication, domestic life, interpersonal interactions and relationships, and community, social and civic life (Scarinci, et al., 2009). Other authors have recommended further exploration of the concept of 'third-party disability' in relation to family members of individuals with Alzheimer's Disease (Byrne & Orange, 2005) and siblings of a child with unintelligible speech (McLeod, 2006).

Two recent systematic reviews revealed the effects of aphasia on family members through extraction of findings from the literature and mapping them to the ICF (Grawburg, et al., 2012, 2013a). These reviews showed that aphasia is associated with changes in family members' functioning and disability, in addition to contributing to the development or worsening of health conditions. In the precursor to the present study, interviews with family members were analysed to reveal the changes they experienced secondary to their significant other's aphasia. These were categorised as positive/neutral or negative aspects of emotions, communication, relationships, recreational activities and social life, and paid/volunteer work or education. Family members experienced additional negative changes categorised as domestic and caregiving responsibilities, finances, and physical and mental health (Grawburg, et al., 2013b). These categories were broadly associated with the ICF domains of mental functions, communication, domestic life, interpersonal interactions and relationships, major life areas, and community, social, and civic life. The current study aimed to expand these results to increase our understanding of 'third-party functioning and disability' in aphasia and provide justification for application of the ICF to family members.

## 5.3 METHOD

### 5.3.1 Study Design

This is the first phase of a mixed methods study with the overall aim of developing a measurement tool for describing the nature and extent of changes to family members' functioning and disability due to aphasia. This phase of the study implemented an inductive design with qualitative description as the research strategy to reveal key issues from statements of the participants that may not have been exposed or examined before (Sandelowski, 2000; Thomas, 2003). The key issues

were coded using qualitative content analysis then mapped onto the ICF. In-depth description of the qualitative analysis has been reported elsewhere (Grawburg, et al., 2013b).

### 5.3.2 Participants

Family members and people with aphasia were recruited through community stroke groups and speech-language pathologists. Maximum variation sampling was selected to ensure diversity among participants (Patton, 2002) with variation sought for the participants with aphasia in relation to gender, age, aphasia post-onset time, severity of aphasia, and non-communication stroke-related deficits. Eleven participants with aphasia due to stroke were recruited. The characteristics of these participants are displayed in Table 5.1. Family members were able to directly volunteer their participation and were identified by participants with aphasia through use of the Social Network Convoy Model (Antonucci & Akiyama, 1987). All those who volunteered were included. Characteristics of the twenty family members who participated in the study are displayed in Table 5.2.

Table 5.1.

*Characteristics of participants with aphasia (n=11).*

| | Mean or frequency | Standard deviation or % | Range |
|---|---|---|---|
| Gender | | | |
| Male | 6 | 55% | |
| Female | 5 | 45% | |
| Age (years) | 71.09 | 21.04 | 18 - 88 |
| Aphasia post-onset time (years) | 7.5 | 10.91 | 1 - 40 |
| Aphasia quotient (WAB-R) | 74.5 | 24.77 | 14.1 - 98.6 |
| Burden of stroke (BOSS) | 34.8 | 16.82 | 12.89 - 55.86 |

Aphasia Quotient (WAB-R) = Summary score on the Western Aphasia Battery-Revised (WAB-R), indicating level of aphasia severity (lower scores = greater severity).

Burden of stroke (BOSS) score is based on the Burden of Stroke Scale (BOSS) (higher scores = greater severity).

Table 5.2.

*Characteristics of family member participants (n=20).*

| | Mean or frequency | Standard deviation or % | Range |
|---|---|---|---|
| Gender | | | |
| Male | 6 | 30% | |
| Female | 14 | 70% | |
| Age in years | 51.05 | 21.85 | 13-80 |
| Relationship to PWA | | | |
| Daughter | 5 | 25% | |
| Wife | 4 | 20% | |
| Sister | 3 | 15% | |
| Son | 2 | 10% | |
| Brother | 1 | 5% | |
| Brother-in-law | 1 | 5% | |
| Father | 1 | 5% | |
| Granddaughter | 1 | 5% | |
| Husband | 1 | 5% | |
| Mother | 1 | 5% | |
| Lived with PWA* | 10 | 50% | |

PWA = person with aphasia; FM = family member

*Of the 50% of FMs not living with PWA, the mean distance between FM and PWA's home was 6 kilometres (SD=4.57, Range=0.1-20).

### 5.3.3 Data Collection

Participants with aphasia completed three assessment measures: the Western Aphasia Battery-Revised (Kertesz, 2006) to determine the severity of the language impairment; the Burden of Stroke Scale to measure overall functioning resulting from stroke-related impairments, such as self-care and mobility (Doyle, et al., 2004); and the Social Network Convoy Model to identify family members closest to the person with aphasia (Antonucci & Akiyama, 1987).

Family members identified as being close to the person with aphasia participated in individual in-depth semi-structured interviews. The mean interview time was 42 minutes (SD=0:18, range=0:13-1:11) and mean total contact time was 2 hours: 39 minutes (SD=1:44, range=0:20-5:50). A topic guide was used during interviews to guide family members in their description of how they had been affected by having a relative with aphasia. The topic guide included open-ended statements, such as "Tell me about any changes that have occurred in your life as a consequence of your family member's aphasia," and probe questions, such as "Has having a family member with aphasia affected your mental health in any way?" Though family members were prompted to specifically describe the effects of aphasia on their lives, it is acknowledged that the onset of aphasia coincided with any stroke-related changes, which may make it difficult for family members to identify changes that occurred solely due to aphasia. After interviews were completed and the data were analysed, family members were contacted to participate in member checks. Through this process, family members could clarify, confirm, or modify the cumulative results according to their own experience of having a relative with aphasia, which enhances the rigour of the study (Thomas, 2003). Trustworthiness of the results were also improved through peer debriefing (Lincoln & Guba, 1985), documentation of the research process (Glogowska, 2011; Graneheim & Lundman, 2004; Mertens, 2010), and maintenance of an audit trail (Lincoln & Guba, 1985). Reflexivity, the acknowledgement of researcher bias, was addressed through discussion of the authors' previous experience with the ICF and clinical work with family members of people with aphasia (Sandelowski & Barroso, 2002).

### 5.3.4 Data Analysis

Interviews were transcribed verbatim as specified by Poland (2001) and analysed using qualitative content analysis according to the guidelines set by Graneheim and Lundman (2004) to identify key statements and develop codes for how family members are affected by having a relative with aphasia. Two researchers independently mapped these codes to the ICF according to ICF linking rules outlined by Cieza and colleagues (2005) and reached 90% agreement. Disagreements were resolved through discussion and consensus with a third researcher.

## 5.4 RESULTS

Analysis of the interviews identified 124 codes. Of these, 32 codes were mapped to the Body Functions component and 85 to the Activity and Participation component within the Functioning and Disability part of the ICF. Six of the remaining codes were mapped as health conditions, but not classified further. Health conditions are classified by the *International Statistical Classification of Diseases and Related Health Problems, 10th Revision* (ICD-10) and not by the ICF. The last remaining research code, "Life changes-because of aphasia there is a new normal" was classified as "not definable-quality of life" in adherence to the ICF linking rules (Cieza et al, 2005).

### 5.4.1 Health conditions

Family members reported the development or exacerbation of health conditions they attributed to aphasia, including depression, anxiety, vertigo, ulcer, hypertension, and mental health changes. The 79-year-old wife of a man with aphasia described the recurrence of pre-existing depression related to aphasia and the 60-year-old daughter of a woman with aphasia said, "*Oh, I'm sure I must have some kind of depression. I'm certain about that…*" The daughter of a woman with aphasia described increased levels of anxiety due to aphasia and the husband of a woman with aphasia said his doctor prescribed medication to help him calm down. One family member reported the development of an ulcer following his son's aphasia and another said she was diagnosed with hypertension subsequent to the onset of her mother's aphasia. The 51-year-old wife of a man with aphasia described the recurrence of

vertigo, "*I did get vertigo, gosh two weeks after* [husband's name] *had his stroke*. *Um stress probably brought it on I suspect."* Other family members described changes in their own mental health and the mental health of other relatives due to aphasia. The 47-year-old mother of a man with aphasia said, "*I know he* [the participant's husband] *really worries about my mental health…. Probably because I find with aphasia no one understands… the constant pressure of communication, being that communication facilitator of a person with aphasia."*

### 5.4.2 Body Functions component

Table 5.3 displays the relevant ICF domain and ICF code and code name within the Body Functions component with the associated research code and a sample participant quote. Changes mapped to Body Functions were linked to the domains of a) Mental functions and b) Functions of the digestive, metabolic and endocrine systems. A summary of the specific findings is presented below.

a) *Mental functions*. Family member reports mapped to the mental functions domain reflected changes to emotions, energy, sleep, thinking, memory, and self-awareness. Family members experienced a range of positive and negative emotions they attributed to the aphasia. Most felt worried about the person with aphasia and some felt that aphasia made them more appreciative. Family members conveyed that they were extremely tired because of the aphasia, while others experienced difficulty getting enough rest and one required medication to help. Several family members experienced changes to thinking and memory and found that their ability to focus and concentrate was impaired. Some family members felt their ability to focus improved as they adjusted to aphasia, whereas others felt that the impact of aphasia was cumulative and their attention and memory deteriorated over time. They attributed negative changes to stress related to aphasia. Many reported learning about themselves, such as the mother of a young man with aphasia, *"… I've grown a lot more as a person, through… aphasia."*

b) *Functions of the digestive, metabolic and endocrine systems*. Some family members experienced excessive changes in their weight. Weight loss attributed to aphasia was related to stress while weight gain related to reduced time for fitness and meal preparation.

Table 5.3.

*Research findings mapped to the Body Functions component of the ICF.*

| ICF domain | ICF code & code name | Associated research codes | Sample participant quote |
|---|---|---|---|
| Mental Functions | b122 Global psychosocial functions | • Grew up more quickly | *"… if he hadn't had his stroke and aphasia and stuff, then I wouldn't be quite so independent and I'd be relying on him more."* - 17-year-old son |
| | b1260 Extraversion | • Inhibited | *"…the charades, filling in for mum. That… inhibited me."* - 59-year-old daughter |
| | b1264 Openness to experience | • Less desire to socialize | *"…I've sort of left it up to him* [participant's husband] *to maintain relationships* [with friends]*, invite people around, and… make sure we keep in touch."* - 36-year-old granddaughter |
| | b1263 Psychic stability | • Irritated<br>• Overwhelmed<br>• Stressed<br>• **Worry** | *"I remember being very worried that if something did happen* [person with aphasia] *couldn't call for an ambulance."* - 51-year-old wife |
| | b1265 Optimism | • Hopeful<br>• **Learned to focus on the positive**<br>• Stroke has put things into perspective | *"… we just relish, we get so… excited about these tiny steps that nobody else would notice."* - 48-year-old father |
| | b1300 Energy level | • Tired | *"… it was exhausting. I'd go to bed just feeling like my brain was coming out my ears… from trying to figure out what he was saying."* - 47-year-old mother |
| | b134 Sleep functions | • Change in sleeping patterns | *"… he* [the doctor] *gives me sleeping tablets"* - 60-year-old daughter |
| | b140 Attention functions | • Hard to focus or concentrate | *"…I just wasn't able to concentrate as much."* - 13-year-old son |
| | b144 Memory functions | • Memory got worse | *"I found my memory has got very bad in the last few years… I think there's a lot of stress factors involved in that..."* - 51-year-old wife |
| | b152 Emotional functions | • Afraid<br>• Angry<br>• **Appreciative**<br>• Embarrassed<br>• Frustrated<br>• Grief<br>• Guilty | *"… it* [aphasia] *has made us appreciate what we have."* - 48-year-old daughter |

| | | | |
|---|---|---|---|
| | | • Jealous<br>• Proud<br>• Sad<br>• Sympathetic for PWA<br>• Shocked<br>• Uncertain<br>• Laughter | |
| | b1521 Regulation of emotion | • More emotional | *"… we'll... get emotional about it, we'll have a cry from time to time… you find the emotions of* [person with aphasia]*'s stroke just… sitting under the surface so… sometimes it'll be a trigger… and you'll have a cry and then you get over it."* – 48-year-old father |
| | b1644 Insight | • Learned about myself | *"… I've become a stronger person. I mean, I never thought I could sell a house or do all the arrangements and I did that. Everything! I never ever thought I could do it."* |
| | b1646 Problem-solving | • Problem-solving | "*it's also made us grow a lot… calling on our own reserves of… logic and… lateral thinking, that's actually all helped us as well."* |
| Functions of the digestive, metabolic and endocrine systems | b530 Weight maintenance functions | • Weight loss/**gain** | *"…I've found myself um, getting a bit weighty where I shouldn't be.*" - 64-year-old husband |

PWA=Person with aphasia; FM=family member

Sample participant quote corresponds to the **bolded research code.**

### 5.4.3 Activities and Participation component

Table 5.4 displays the results of mapping research codes to the Activities and Participation component of the ICF with a sample participant quote. Research findings were mapped to eight of the nine domains in the Activities and Participation component, including a) Learning and applying knowledge, b) General tasks and demands, c) Communication, d) Self-care, e) Domestic life, f) Interpersonal interactions and relationships, g) Major life areas, and h) Community, social and civic life. According to analysis of interviews with family members, the only domain not affected by aphasia was mobility. The research code "Change in physical intimacy between the family member and the person with aphasia" was mapped to both d7750 Family relationships and d7702 Sexual relationships to reflect changes in ways that affection is shared between family members (i.e., increased physical touching instead of verbal expressions of love) and also changes in intimacy between spouses.

The summary of the findings are included here and categorized according to the corresponding ICF domain within the Activities and Participation component:

a) *Learning and applying knowledge*. Family members indicated that they needed to consider their relative with aphasia when planning and making decisions in various aspects of their lives. For example, family members described organizing their day so they could help the person with aphasia go shopping while they did their own shopping. Others described negotiating timing of vacations or their work hours to ensure other family members could support the person with aphasia while they were away.

b) *General tasks and demands*. Family members experienced difficulty coping and sometimes felt overwhelmed by the changes that occurred as a result of aphasia and the accompanying feelings of stress and pressure. They described how these difficulties affected many other domains of their lives including their relationships with others and time for personal activities such as self-care, work, and recreational activities.

Table 5.4.

*Research findings mapped to the Activities and Participation component of the ICF.*

| ICF domain | ICF code & code name | Associated research codes | Sample participant quote |
|---|---|---|---|
| Learning and applying knowledge | d177 Making decisions | • Change in planning and decision-making | *"In terms of making sure* [person with aphasia]*'s welfare is managed effectively and appropriately and sensitively… when it comes to family decisions and that will affect the my decision making."* - 48-year-old father |
| General tasks and demands | d240 Handling stress and other psychological demands | • Difficulty dealing with aphasia<br>• Learned to cope with sadness, loss, and grief | *"…that was very hard because she couldn't really consent to anything. I think that… was one of the things that I found difficult to deal with… the fact that someone who's very private no longer had the power of speech to be able to say, "Well actually, I don't want to do this."*- 48 year old daughter |
| Communication | d350 Conversation | • Conversational skills got worse | *"… our* [conversational] *skills sometimes went a bit downhill cause, it's like talking to… a 2-year-old again."* **-** 15-year-old sister |
| | d3503 Conversing with one person | • **Change in content of communication with PWA**<br>• Communicating with PWA in a new way<br>• Difficulty communicating with PWA | "…he used to explain to me a lot more than show me… but now… because it's harder to talk and that, he'll just do it himself or not do it." - 13-year-old son |
| Self-care | d5701 Managing diet and fitness | • **Less exercise**<br>• Poor/improved diet | *"I used to go to an exercise class twice a week… And it just got that way that they all have appointments or I had to visit or I had to do something for everybody and, of course, it went by the by…"*- 65-year-old sister |

| | | | |
|---|---|---|---|
| Domestic life | d610 Acquiring a place to live | • Changes to living arrangements | *"…we've sold both of those* [family member's own house and person with aphasia's house] *…I couldn't just sell Mum's and still continue to live there* [on the same property]." - 60-year-old daughter |
| | d620 Acquisition of goods and services | • Got new things | "*…Auntie got a Wii for us, for* [person with aphasia]…*"* – 15-year-old sister |
| | d6200 Shopping | • Increase in shopping | *"…I probably get out of the house at least once a day, because I got to go shopping."* – 64-year-old husband |
| | d630 Preparing meals | • Increase in planning meals, cooking and baking | *"I didn't necessarily cook bad food but I probably didn't plan to have, um, fish once a week, chicken twice a week and steak once a week and a whole stack of vegies… We tended to eat um, pasta dishes with a sauce… so that's one lifestyle* [change]*…I plan… the weekly menu to try and make sure we get a good balance of the right types of food."* 51-year-old wife |
| | d640 Doing housework | • Increase in housework<br>• **Increase in cleaning**<br>• Making the bed | *"I'm chief cook and bottle washer…"* - 64-year-old husband |
| | d6400 Washing and drying clothes and garments | • Increase in washing and ironing | "*…if there was a jersey he* [the person with aphasia] *wanted washed and he'd send it over to me."* - 75-year-old sister |
| | d6401 Cleaning cooking area and utensils | • Doing the dishes | "*Whereas, we shared the work before. You're sort of doing twice as much. A well as looking after somebody….um, like even getting the meals and doing the dishes…"* - 79-year-old wife |
| | d6505 Taking | • Gardening and tending plants | *"… there is a lot of lawn mowing and edges and trimming of* |

| | | | |
|---|---|---|---|
| | care of plants, indoors and outdoors | | *shrubs and bushes and… you've gotta keep doing it…"* - 64-year-old husband |
| | d6506 Taking care of animals | • Feeds the animals | *"… just mowing the lawn, feeding the animals more…"* - 13-year-old son |
| | d660 Assisting others | • Arranging employment for PWA<br>• Becoming caregiver of PWA<br>• **Caring for other FMs**<br>• Helped people with aphasia<br>• Supporting PWA's education | *"…I sort of try and help with what I can, where I can… I probably don't lift the burden* [from the person with aphasia's daughter] *that much. … but with my Mum not being around… I wanted to be involved on her behalf… to support my Aunt."* – 36-year-old granddaughter |
| | d6601 Assisting others in movement | • Must always be the designated driver<br>• **Transporting PWA and others places** | *"… so the different part is probably the transport… we used to take turns with the car… now I do it… he wanted a battery in his watch, and then we wanted groceries…. so we went and got them."* - 80-year-old brother-in-law |
| | d6602 Assisting others in communication | • **Assisting PWA to communicate with medical professionals**<br>• Practicing communication with PWA<br>• Assisting PWA with expressive communication<br>• Communicating with extended family on behalf of PWA<br>• Communicating with medical professionals on behalf of PWA<br>• Communicating with the public on behalf of PWA<br>• Encouraging PWA's independent communication<br>• Explaining aphasia to others<br>• Helping PWA to understand complex household decisions<br>• Interpreting PWA's intended communication | *"… there's this constant thing of having to be called on… the focus always comes to me to be the one to communicate or deal with things… we go to a private physio and he understands… pretty well, but even he has to check it out with me sometimes…"*– 51-year-old wife |

| | | | |
|---|---|---|---|
| | | message<br>• Introducing PWA to materials, strategies and adaptations to assist with communication<br>• Making phone calls for PWA<br>• Speaking on behalf of PWA | |
| | d6603 Assisting others in interpersonal relations | • **Being a source of social contact for PWA**<br>• Supporting PWA's social activities | "…[the person with aphasia] *doesn't have that* [a social life] *full stop....he therefore relies on us a lot more… we'll watch telly together or we'll talk or play some games.*" – 48-year-old father |
| | d6605 Assisting others in health maintenance | • Actively supporting speech therapy | *…I sit with him* [the person with aphasia] *every session. I never have not sat in at speech therapy session...I… don't know how you can translate what he's learning across if he can't tell me what he's doing…"* – 47-year-old mother |
| Interpersonal interactions and relationships | d7102 Tolerance in relationships | • Less judgmental and more tolerant of others | "*It's made me not jump to conclusions meeting people… It's given me a whole new… patience… understanding, and tolerance of people that may not be able to speak or… have a physical disability…"* - 55-year-old daughter |
| | d7500 Informal relationships with friends | • Change in relationship with friends<br>• Made new friends and met new people | "*…we've got the same friends… but they don't come as often… I just feel they haven't got patience waiting for* [the person with aphasia] *to tell him what he wants to say."* – 79-year-old wife |
| | d760 Family relationships | • Change in activities shared with FM and PWA<br>• Change in amount of time spent with PWA<br>• Change in family roles<br>• Doing special things for PWA<br>• Family is closer<br>• Family spends more time together<br>• **FM is closer/not as close to PWA** | "*… So Mum and I, didn't do well for a while. We struggled. Mum struggled with me being horrible and I struggled with her inability to communicate."* – 62-year-old daughter |

| | | | |
|---|---|---|---|
| | | • FMs support each other and work together<br>• Overprotective of PWA<br>• PWA has become a priority in FM's life | |
| | d760 Family relationships AND<br><br>d7702 Sexual relationships | • Change in physical intimacy between FM and PWA | *"The, um, emotional side as far as a couple has gone. No no touching, no sex, no nothing. That all went."* - 80-year-old wife |
| | d7600 Parent-child relationships | • Change in relationship with children | "*… our tolerance to that isn't as good as it would have otherwise been… there may be… less patience, a little bit more frustration… directed particularly to those two kids* [family member's children who do not have aphasia]*… which… I don't think would have been nearly as much if we hadn't have had* [the person with aphasia]'s *aphasia and stroke to cope with."* - 48-year-old father |
| | d7601 Child-parent relationships | • Change in relationship with parents | *"…my dad and I would talk… We'd communicate. Mix with my dad… I was working with dad because mum couldn't."* - 59-year-old daughter |
| | d7602 Sibling relationships | • Change in relationship with siblings | *"… I would have done that with Dad* [the person with aphasia], *but I've done that with my brother instead. He's… stepped up to be Dad… I would rather talk to him about that stuff than I would with my parents… …if Dad hadn't had his stroke and aphasia, we wouldn't a been quite as close."*-17-year-old son |
| | d7603 Extended family | • **Change in relationship with extended family**<br>• Less contact with extended family | *"… our relationship with our outer family, with my cousins, it came more closer…"*– 15-year-old sister |

| | | | |
|---|---|---|---|
| | relationships | | |
| : | d7701 Spousal relationships | • Change in relationship with spouse<br>• PWA and FM got married | "*I'd get really angry with him* [family member's husband]… *I'd remind him, "Hey, she's* [the person with aphasia] *really sick, she's scared, and she's old… I just had to realize that sometimes I had to put him first."* – 36-year-old granddaughter |
| Major life areas | d810 Informal education | • Aphasia became focus of education/training<br>• **Learned about aphasia and stroke**<br>• Learned more about elderly care | "*… it does give you this amazing insight. I had no idea about it* [aphasia] *before, I've been a nurse for twenty-five years. I had no idea about the dimensions of aphasia. I don't think I'd even heard the word aphasia before*." – 47-year-old mother |
| | d8452 Terminating a job | • Quit job | *"I actually went [quit] nursing, which I loved… it was too much… I needed to be helping out more at home."* – 55-year-old daughter |
| | d850 Remunerative employment | • **Change in work timetable**<br>• Professional development<br>• Took extended time off work<br>• **Worked fewer hours**<br>• Worked from home | "*… I came back to a reduced workload in three months. I went back to a four day week, which was a thirty-two hour week and then, after a few months I went back to a forty hour week, a bit over four days, so four ten hour days."* - 48-year-old father |
| | d855 Non-remunerative employment | • Stopped volunteering<br>• **Volunteering for an organization to support people with brain injury and/or aphasia** | "*…I'm helping… the cause of aphasia just by participating in research and… getting myself in under MRIs … being a control……I feel positive about… and… involvement and the contribution that I'm making… to* [the national Aphasia Association]… *also involved in try*[ing to] *establish(ed) … coffee groups, support groups for people with aphasia."* - 64-year-old husband |
| | d870 Economic self-sufficiency | • Less spending money | "*… my personal spending that was diminished."* – 36-year-old granddaughter |
| | d8700 Personal economic | • Financial effects of buying necessities for PWA<br>• Increased petrol costs<br>• **Loss of PWA's income** | *"For the first 10 week… there was no income… Cause we didn't even qualify for government assistance because of* [the person with aphasia]*'s level of income prior to the stroke… And to go* |

| | | | |
|---|---|---|---|
| | resources | | *right down to having… $20 000 a year is is…. A big shock."* - 51-year-old wife |
| Community, social and civic life | d920 Recreation and leisure | • **Less time for self and independent activities**<br>• Little time for recreational activities<br>• Reduced number of vacations | *"… I just don't think to, sit down and relax during the day… there's always, something that's, got to be done."* – 64-year-old husband |
| | d9201 Sports | • Change in types of sports activities | *"… we slowed down on our swimming… … started a futsal team…"* – 15-year-old sister |
| | d9204 Hobbies | • Change in types of hobbies | "*Because* [person with aphasia] *can't sit and read… and therefore, I don't sit and read much either."* – 79-year-old wife |
| | d9205 Socializing | • Fewer social activities | *"…social activities changed very significantly initially… I was careful about not… doing something every weekend… I try to plan around all of that and not load up too much so socially…"* – 51-year-old wife |

PWA=Person with aphasia; FM=family member

Sample participant quote corresponds to the **bolded research code.**

c) *Communication*. Family members explained that their communication with the person with aphasia changed in many ways. This included differences in the way they communicated with the person with aphasia and changes to the content of their communication with them as well as a decline in their own conversational abilities. Communication changes were associated with relationship changes and the need to provide the person with aphasia with additional support.

*d) Self-care*. Family members noticed changes in the quality of their diets at home (i.e. some prepared less healthy meals, while others ate more healthily) and often had less time and energy for maintaining their fitness through exercise.

e) *Domestic life*. Family members reported an increase in a variety of domestic duties from cooking and shopping to gardening and feeding the animals. The most common responsibility was to provide assistance to the person with aphasia in multiple capacities. For example, family members provided social contact for their relative with aphasia and helped their relative with aphasia communicate. Support for participating in speech therapy was also commonly provided by family members. In addition to assisting the person with aphasia, many family members also reported that they needed to watch out for other relatives who experienced difficulty due to the aphasia. Finally, aphasia was associated with changes to living arrangements, such as moving house.

f) *Interpersonal interactions and relationships*. Aphasia affected the relationship between the family member and the person with aphasia, as well as many of the family member's relationships with other relatives and friends. Some family members whose parent had aphasia felt there was a role reversal between themselves and their parent. Most participants found that the person with aphasia had become more dependent on them. Other family members

explained that their relationship with other relatives changed, such as when the relationship between brothers was strengthened following their father's aphasia. A few family members relied more strongly on their friends for support, but many others found that their friends did not understand aphasia and became less close to them.

g) *Major life areas*. Changes in household income were reported when the person with aphasia was unable to return to work after the stroke and when the family member worked less or needed to change jobs because of the caregiving duties associated with aphasia. A decrease in household income had more substantial consequences when the person with aphasia had been the primary income earner at the time of the stroke. The effect of reduced income was worse when increased spending due to aphasia-related costs were considered. Family members reported that their personal spending was diminished as they needed to spend more money on petrol for taking the person with aphasia places and driving to see them more often.

Many family members described taking up volunteer work related to aphasia, though some found they had to give up volunteer work they had done prior to their relative's aphasia. Most family members made an effort to learn more about aphasia, either through formal education or informal independent research.

h) *Community, social and civic life*. Time for self, recreational, and social activities were affected by the aphasia. Many family members found they had less time for themselves and their own activities and that they had become less active socially. In some cases, family member's hobbies and sports changed in alignment with the person with aphasia's abilities. Family members noted that they were able to take fewer holidays because of the aphasia.

## 5.5 DISCUSSION

In response to the research agenda in the ICF and communication disorders, this study presents preliminary evidence for the nature of 'third-party functioning and disability' in family members of people with aphasia (Threats, 2010; Worrall & Hickson, 2008; WHO, 2001). The results show that aphasia affects the health, functioning, and disability of family members, providing support for the model of 'third-party disability' developed by Scarinci, et al. (2009) and justification for the inclusion of family members within the scope of the ICF in keeping with its "universal application." The pervasive positive, negative, and neutral effects of aphasia on family members are illustrated with research codes being mapped to ten of the domains within the Body Functions and Activities and Participation components of the ICF. Notably, family members associated the development or exacerbation of a health condition with their relative's aphasia. Overall, the findings demonstrate that 'third-party functioning and disability' can be attributed to the health condition of a significant other.

Use of the ICF to classify changes to family members' functioning and disability as a consequence of their significant others' health condition, a condition that they themselves do not have, is not well-established beyond the field of communication disorders. Indeed, it may be debatable that the ICF should be applied to those without the health condition. On the other hand, we have provided a comprehensive argument for use of the specific term and concept of 'third-party functioning and disability' and continue the discussion in consideration of the study findings and implications of 'third-party functioning and disability' for policy development and rehabilitation planning.

A clear description of 'third-party functioning and disability' within the framework of the ICF provides a consistent health-based rationale for including family members in rehabilitation and offers evidence for the provision of services for family members from a funding and policy perspective. Though future research may establish long-term cost savings with a family-centred approach, current payment and reimbursement policies need to acknowledge increased time and spending required to include family members (Kuo et al., 2012). Policies also need to be flexible to allow for individual and family differences. The eventual classification of personal factors within the ICF may clarify the role of personal differences in family-centred care.

The ICF is designed to be used by rehabilitation professionals for goal-setting and monitoring (Üstün, Chatterji, Bickenbach, Kostanjsek, & Schneider, 2003). Thus, it is appropriately applied in the implementation of family-centred care as all those whose functioning and health are impacted by a health condition may benefit from rehabilitation within the health system (Gagné, 1998; Gagné, Hétu, Getty, & McDuff, 1995; Hétu, Jones, & Getty, 1993; Scarinci, et al., 2012). Family centred-care has most often been applied in the area of paediatric health services (Kuo, et al., 2012); however, some of its principles may work to maximize 'third-party functioning' and minimize 'third-party disability' in family members of adults with aphasia. Provision of family centred-care in aphasia could involve information sharing and decision-making between professionals, the person with aphasia, and family members, with consideration of personal differences such as care preferences, culture, skills, and expertise (Kuo, et al, 2012). Specific service delivery changes that may occur in recognition of 'third-party functioning and disability' in aphasia would involve systematic inclusion of family members on clinical caseloads for assessment, intervention, or referral at all stages of care, including routine follow-up to maintain functioning and provide early intervention to cope with the changing impact of aphasia over time (e.g., related to transition from working to retirement, reduced support, development of health conditions that change the communication environment, etc.). In addition to offering communication training and rehabilitation services to family members, speech-language pathologists may provide links to community support (e.g., peer groups, volunteer organizations, and respite care) and facilitate family member presence on policy advisory boards, as contributors to clinician education (e.g., family members presenting at grand rounds and in medical training courses), and as consultants to clinical staff (Kuo, et al., 2012). 'Third-party functioning and disability' should be incorporated into the curriculum for educating future clinicians.

An understanding of 'third-party functioning and disability' in the context of the ICF is also important in preventing health conditions. As shown in this study and described in the ICF, disability may affect the development or progression of a health condition (WHO, 2001) through the causal relationship between psychological disorders (i.e., stress) and physical disorders (Bevans, 2012; McEwen, 2006; Threats, 2010). In addition, supporting family members to prevent or minimize 'third-party

disability' is likely to have a positive impact on the health of the community and people with disabilities. From the perspective of the ICF, the family member may act as an environmental factor (e.g., e310 Immediate family or e315 Extended family) that can be a barrier or facilitator to the person with aphasia's functioning and recovery (Scarinci, et al., 2012). According to people with aphasia, family members may act as facilitators by being present to support the person with aphasia and providing them with social contact (Howe, Worrall, & Hickson, 2008). Further, studies of people with stroke who perceive themselves to be well supported have improved psychological (Hilari, et al., 2010) and physical recovery (Tsouna-Hadjis, Vemmos, Zakopoulos, & Stamatelopoulos, 2000). In some cases, the person with the communication disability may experience fewer difficulties because of the accommodation of the family member (e.g., answering telephone and assisting in communicating with others) (Hétu, Riverin, Lalande, Getty, & St-Cyr, 1988). In contrast, if a family member develops 'third-party disability' secondary to aphasia they may be unable or less able to act in the role of informal support person, consequently becoming a barrier to the person with aphasia's functioning (Howe, et al., 2008).

A comparison of the findings of this study and previous studies investigating 'third-party disability' in hearing impairment indicate that aphasia has a more extensive impact on family members with a greater number of ICF domains affected including areas of body functioning (i.e., mental functions and functions of the digestive system), Activities and Participation (i.e., learning and applying knowledge, general tasks and demands, self-care, major life areas), and onset or exacerbation of health conditions. Consistent with the findings from the precursor to this study, this investigation reveals previously unreported positive effects of aphasia such as increased pride in oneself and the person with aphasia, focusing on the positive, laughter, learning about oneself, becoming more tolerant of others, and volunteering to help people with aphasia. Previously unreported negative effects of aphasia identified in this study include diminished memory and focus, weight loss/gain, changes to planning and decision-making, and the responsibility of supporting the person with aphasia to socialize. In the context of the ICF, the negative effects on family members reported here are similar to the handicaps classified according to the

ICIDH by Le Dorze and Brassard (1995) with additional identification of changes to finances, health, and supporting others.

Previous research has suggested that family members' experience of aphasia may be influenced by their gender (Bakas et al., 2006; Kinsella & Duffy, 1978; Pringle et al., 2010), age (McGurk & Kneebone, 2013)], whether or not they live with the person with aphasia (Brown et al, 2011; Franzén-Dahlin, et al., 2008; Howe et al., 2012), the nature of the relationship between the family member and the person with aphasia (Hemsley & Code, 1996), and the level of support required by the person with aphasia (Bakas et al, 2006; Franzén-Dahlin, et al., 2008; Ross & Morris, 1998). In this study, older family members were less likely to report changes to employment or finances, most often because the onset of aphasia occurred after retirement. Similarly, only family members participants 18 years and over reported changes to health and physical functioning. In addition, although all types of family members reported changes in their relationship with the person with aphasia, only spouses reported a feeling of loneliness and decreased physical intimacy. Variable changes based on relationship type were not noted in other areas, demonstrating that all family members, not just spouses, may experience widespread effects of aphasia. This study also corroborated research suggesting that increased dependency of the person with aphasia was associated with a negative impact on family members. In the next quantitative phase of the study, analysis will be conducted with a larger number of family members to better understand the influence of personal characteristics on third-party functioning and disability.

### 5.5.1 Limitations and future research directions

As the first phase of a sequential mixed methods study, the qualitative outcomes presented here provide the foundation for developing a tool to measure 'third-party functioning and disability' in aphasia and confirm or clarify these results for generalisation to the larger population of family members of people with aphasia (Giddings & Grant, 2009; Scarinci, et al., 2011). While generalisability is not the aim of qualitative research, *transferability* is an important aspect of ensuring trustworthiness of qualitative findings. In this study, transferability was achieved through a clear description of the participants, allowing readers to assess the

applicability of the findings to different contexts (Graneheim & Lundman, 2004; Mertens, 2010). Changes to functioning and disability revealed here may be unique to family members of people with aphasia due to the nature of the disorder and may not be relevant to family members of people with other health conditions. For example, compared to family members of people with stroke without aphasia, family members of people with aphasia may experience greater emotional changes (Artes & Hoop, 1976), more significant changes to their job (Herrmann, et al., 1995), and poorer social adjustment (Kinsella & Duffy, 1979). As communication is an aspect of most life situations, the broad range of effects of aphasia on family members demonstrated in this study is understandable. However, despite being asked to focus on the changes they experienced because of *aphasia,* family members may not have been able to separate the influence of aphasia from that of the stroke as a whole. This difficulty has been reported in other qualitative investigations of family members of people with aphasia (Barrow, 2008; Le Dorze & Signori, 2010; Grawburg, et al., 2013b). Consequently, while some of the findings may apply only to family members of people with aphasia, it is likely that many are also applicable to family members of people with stroke and possibly other health conditions. This issue warrants specific investigation in future studies with family members of people with health conditions other than aphasia.

Four of the research codes generated were mapped to the ICF, despite concerns that their meanings were incompletely conveyed by the existing ICF codes. First, family members described "Changes to their living arrangements" that went beyond d610 Acquiring a place to live, which includes only buying, renting, and furnishing a dwelling, but does not include other changes such as living with more or fewer people and the need to make alterations to the house because of disability. Next, a more appropriate code for "Professional development" may be a specific education code (in addition to d810-d839) or an additional remunerative employment code for advanced career training. And finally, "Supporting the person with aphasia's education" and "Arranging employment for the person with aphasia" were both assigned the code of d660 Assisting others, though it may be more appropriate to have additional codes in this section to account for assisting others in various ways (e.g., education and assisting others in securing employment). Further research and development of the ICF may alleviate these types of coding concerns.

## 5.6 CONCLUSION

Despite reservations over the term ‘third-party disability’ or ‘third-party functioning and disability’, implementation of this concept and use of a specific label endorsed by the WHO through the ICF framework underscores the significance of the pervasive effects on family member’s functioning, disability, and health that are associated with the health condition of their significant other. By mapping the results of this study to the ICF, we have not only demonstrated how aphasia can act as an environmental factor that impacts upon the health and functioning of family members, but we have identified some of the rehabilitation needs of family members. The results also emphasize the importance of offering support specifically for family members in a model of family-centred care and provide a foundation for further research into ‘third-party functioning and disability’. Recognition that ICF domains of health are impacted by a significant other’s health condition may provide better access to rehabilitation for family members through improved clinical knowledge, policy, and funding, with positive outcomes for people with aphasia and their family members. At a minimum, the ICF provides a “starting point” with an established structure for investigating ‘third-party functioning and disability’ in family members of people with aphasia (Threats, 2010).

# CHAPTER 6

## DEVELOPMENT OF THE SOS-APHASIA: A MEASURE OF THIRD-PARTY FUNCTIONING AND THIRD-PARTY DISABILITY POST-STROKE

## 6.1 ABSTRACT

Background: Aphasia can have a significant impact on the functioning and health of family members with implications for their ability to support the person with aphasia. The effect of aphasia on family members is known as third-party functioning and disability, identified as an area for future research in the International Classification of Functioning, Disability and Health (ICF).

Purpose: The aim of this study was to develop and validate a measure of third-party functioning and disability in family members of people with aphasia post-stroke.

Method: A mixed-methods approach was used to develop the Significant Other Scale for family members of people with Aphasia (SOS-Aphasia). Items for the instrument were generated from qualitative interviews. The 34-item SOS-Aphasia was then completed by 104 family members of people with aphasia for psychometric testing including factor, Rasch, feasibility, and reliability analyses.

Results: Five subscales of the SOS-Aphasia were identified through factor analysis, each of which underwent separate Rasch analysis. Ten of the original 34 items were deleted from the final version of the SOS-Aphasia based on factor loadings and goodness-of-fit criteria. After removal of those items, adequate internal construct validity of each factor was confirmed with Rasch analysis. The SOS-Aphasia items covered the range of third-party functioning and disability. Acceptable test-retest reliability and feasibility was demonstrated at the item and subscale level.

Conclusion: There is preliminary evidence that the SOS-Aphasia is a valid and reliable tool for measuring third-party functioning and disability in family members of people with aphasia. Use of the SOS-Aphasia may facilitate family-centred care in aphasia post-stroke.

## 6.2 INTRODUCTION

Aphasia is a language disorder most commonly caused by stroke. The incidence of aphasia due to stroke is estimated to be 43 to 60 per 100 000 people per year (Dickey, et al., 2010; Engelter, et al., 2006). Family members of people with aphasia experience pervasive changes to their own functioning and health as a result of aphasia, including changes in their ability to work, interact with others, and take care of their own health (Grawburg, et al., 2013b, 2013c; McGurk & Kneebone, 2013). Moreover, some research has indicated that the impact of stroke on family members is more severe when aphasia is present (e.g., increased rates of depression) (Artes & Hoops, 1976; Bakas, et al., 2006; and Kinsella & Duffy, 1979). In the International Classification of Functioning, Disability and Health (ICF), the World Health Organization (WHO) introduced the term 'third-party disability' to describe the negative impact of a significant other's health condition on family members (WHO, 2001). Similarly, 'third-party functioning' has been used to describe the positive and/or neutral consequences that family members experience secondary to their significant other's health condition (Grawburg, et al., 2012, 2013b, 2013c).

Family members play a vital role in supporting people with aphasia as they navigate the health system (Le Dorze & Signori, 2010); thus, inclusion of family members in a family-centred care model is likely to result in more positive outcomes for the family member and the person with aphasia. While the impact of aphasia on family members is recognized, family-centred care and policy in this area have not been well established (Dalemans, et al., 2010; Johansson, et al., 2011; Law et al., 2010; Levack, et al., 2009), nor are family members commonly included when measuring outcomes in aphasia rehabilitation (Simmons-Mackie, et al., 2005). This could be attributed to the absence of objective measures that specifically assesses the impact of aphasia on family members (Herrmann, 1997; Le Dorze & Brassard, 1995; Le Dorze, et al., 2008; Michallet, et al., 2001; Rigby, et al., 2009; Rombough, et al., 2006). A scale based on the ICF framework, which sets the international standard for describing health and health-related states, may facilitate improved services for family members through the identification of specific rehabilitation goals, and provide justification for policies that includes family members (Grawburg, et al., 2013c; Tate, 2009; WHO, 2001). Therefore, the aim of this study was to develop and validate a

measure of third-party functioning and third-party disability in family members of people with aphasia due to stroke.

## 6.3 METHOD

The Significant Other Scale for family members of people with Aphasia (SOS-Aphasia) was developed and validated through a mixed methods approach with an exploratory qualitative-quantitative sequential design (Velozo, Seel, Magasi, Heinemann, & Romero, 2012; Vogt, King, & King, 2004). Qualitative interviews informed the development of the SOS-Aphasia, which was subsequently administered to a group of family members of people with aphasia to facilitate generalisation of the qualitative findings and psychometric testing. The appropriate institutional ethical review boards approved all procedures.

### 6.3.1 Development of the SOS-Aphasia

Items for the SOS-Aphasia were based on the analysis of qualitative interviews with 20 family members of people with aphasia (Grawburg, et al., 2013b, 2013c). Through individual in-depth semi-structured interviews, family members discussed the positive, negative, and neutral effects of aphasia on their lives (i.e., changes in third-party functioning and third-party disability). The codes and categories that represented the full range of the family members' experience were developed into items based on the participants' wording. Table 6.1 presents the original SOS-Aphasia items and demonstrates the association between the items and the qualitative research categories and codes.

Table 6.1.

*SOS-Aphasia items and the corresponding qualitative research codes and categories.*

| **Qualitative Research Category** | **Example qualitative research code** | **SOS-Aphasia Item** |
|---|---|---|
| N/A | N/A | 1. Overall, the effect of my family member's aphasia on my life is… |
| Physical, mental, and emotional health | Depression | 2. My own health has changed. |
| | Fatigue | 3. My body's physical functioning has changed. |
| | Sad | 4. I feel more/less sad. |
| | Stressed | 5. I feel more/less stressed. |
| | Worried | 6. I feel more/less worried. |
| | Embarrassed | 7. I feel embarrassed/proud of him/her. |
| | Frustrated | 8. I feel more/less frustrated, angry, and annoyed. |
| | More emotional | 9. I tend to be more/less emotional. |
| | Appreciative | 10. I feel more/less appreciative. |
| | Hard to focus or concentrate or make decisions | 11. My ability to focus, remember, and/or make decisions has changed. |
| Relationships | Not as close to PWA | 12. My relationship with him/her has changed. |
| | Change in physical intimacy between FM and PWA | 13. There has been a change in the physical intimacy between us. |
| Domestic and caregiving responsibilities | Increased household chores | 14. I am responsible for many household chores. |

| | | |
|---|---|---|
| | Caring for other FMs | 15. I must look out for other family members. |
| | Becoming caregiver of PWA | 16. I have become his/her caregiver. |
| | Helping PWA to understand complex household decisions | 17. I have to manage his/her personal administrative tasks. |
| Communication | Difficulty conversing with PWA | 18. Ease of communication with him/her has changed. |
| | Change in content of communication with PWA | 19. I have to communicate with my family member in a new or different way. |
| Domestic and caregiving responsibilities | Being a source of social contact for PWA | 20. I am the central source of social contact for him/her. |
| | Supporting PWA's social activities | 21. I have to help him/her to socialise with others. |
| | Assisting PWA to communicate with the public | 22. I help him/her to communicate with others. |
| | Actively supporting speech therapy | 23. I help my family member with speech therapy. |
| | Explaining aphasia to others | 24. I explain what aphasia is to others. |
| Relationships | Family is closer | 25. My relationship with other relatives has changed. |
| | Change in relationship with friends | 26. My friendships have changed. |
| Recreational activities and social | Little time for recreational activities | 27. My recreational activities have changed. |

| | | |
|---|---|---|
| life | | |
| | Met new people | 28. My social activities have changed. |
| Finances | Less spending money | 29. I have experienced a change in my finances. |
| Paid/volunteer work or education | Quit job | 30. I have experienced changes to my paid or volunteer work. |
| | Volunteering for an organization to support people with brain injury and/or aphasia | 31. I now help people with aphasia in my paid or volunteer work. |
| | Professional development | 32. I have experienced changes to my education and/or learning. |
| Relationships | Less judgmental and more tolerant of others | 33. My attitude has changed. |
| Emotions | Learned about myself | 34. I have experienced personal changes. |

FM=family member; PWA=Person with aphasia.

The SOS-Aphasia was designed as a self-report questionnaire for family members of people with aphasia. The initial version of the SOS-Aphasia included 34 items, and family members were asked to indicate the effect of having a person with aphasia in their family on their lives over the past month. To control for other influences on the family members' functioning, the SOS-Aphasia instructions stated: "We are interested in finding out what it is like to have a family member with aphasia. We are particularly interested in the effects of aphasia (the communication problem) rather than the stroke as a whole." The first SOS-Aphasia item probed for the family member's assessment of the overall effect of aphasia on their lives. The remaining 33 items began with the statement "Because of my family member's aphasia" followed by the item and, where appropriate, examples generated from the qualitative interviews. For example, "Because of my family member's aphasia, I have to communicate with my family member in a new or different way (e.g., I speak slowly, use shorter sentences, wait to give him/her time to find his/her words)." Respondents were asked to select one option from a 7-point Likert-style rating scale, with intervals and wording based on the qualifiers and anchor points of the ICF, ranging from '-3 a complete problem' to '+3 a complete positive change', with '0' indicating 'no change' (WHO, 2001). To improve the content validity of the SOS-Aphasia (Vogt, et al., 2004), 12 (60%) family members who participated in the qualitative interviews provided feedback regarding the intelligibility and completeness of the format and item content in the initial stages of development. See table 6.1 for the original 34-items.

### 6.3.2 Validation of the SOS-Aphasia

#### *6.3.2.1 Participants*

To facilitate psychometric testing of the SOS-Aphasia, participants with aphasia and their family members were recruited through speech-language pathologists and community stroke groups in New Zealand and Australia. The inclusion criteria for family members were intentionally broad in order to encompass a range of demographic characteristics. Due to previous research suggesting that aphasia can impact all family members (i.e., not only spouses and adults), any close family member who volunteered, irrespective of relationship or age, was included in

the study (Grawburg, et al., 2013b, 2013c). In addition, family members were included whether or not they lived with the person with aphasia, as it has been shown that aphasia affects family members regardless of living situation (Brown, et al., 2011; Grawburg, et al., 2013b, 2013c; Howe, et al., 2012). Specific family member inclusion criteria were: i) identified themselves as being close to the person with aphasia, ii) able to complete the questionnaire in English, and iii) their relative with aphasia met the inclusion criteria for participants with aphasia and also agreed to participate in the study. The aim was to recruit at least 100 family members participants, the minimum suggested for factor analysis and Rasch analysis (Linacre, 1994; Streiner, 1994).

Inclusion criteria for participants with aphasia were: i) aphasia acquired secondary to stroke, ii) 18 years and over, and iii) no dementia according to family member report. Presence of aphasia was confirmed with the Western Aphasia Battery-Revised (WAB-R; Kertesz, 2006). Administration of the WAB-R resulted in the generation of a summary score known as the Aphasia Quotient (AQ). The AQ can range from 0-100 with lower scores indicating greater severity. Based on the AQ, the cut-off for aphasia is 93.8. Aphasia was identified in those with scores above this cut-off when other aphasia-related difficulties were reported, such as word-finding difficulties or problem with reading comprehension. People with aphasia were included regardless of the severity of aphasia, type of aphasia, and post-onset time. In practice, the onset of aphasia and other stroke-related impairments co-occur. Since the SOS-Aphasia was designed to be used by clinicians in real-life situations, people with aphasia with concomitant stroke-related deficits were not excluded. Stroke-related deficits were measured using the Burden of Stroke Scale (BOSS) (Doyle, et al., 2004). The total score on the BOSS served as an indication of the person with aphasia's stroke-related difficulty in the areas of mobility, self-care, cognition, swallowing, energy and sleep, social relations, and mood (Doyle, et al., 2004). People with both aphasia and dementia were excluded, as family members may be unable to discern the influence of cognitive symptoms secondary to dementia from language changes related to aphasia.

All participants gave informed consent. In cases of family members under 18 years old, both the child/teenager and their guardian gave informed consent. Participants with aphasia were given adapted aphasia-friendly information sheets and consent forms, which were designed specifically for people with aphasia by increasing the size of the font, placing a large amount of visual space between sentences, using short simple sentences, and using photographs to enhance the meaning (Rose, Worrall, & McKenna, 2003). Qualified speech-language pathologists, who collected the data, followed the recommended practices (e.g., explaining the written information using short sentences and writing down key words, verifying responses using alternative modes of communication) for obtaining informed consent from individuals with aphasia (Kagan & Kimelman, 1995). People with aphasia were seen in their homes; family members completed the questionnaires in-person, by post, or online.

### 6.3.3 Statistical Analysis

The statistical analysis of the SOS-Aphasia included: 1) exploratory factor analysis; 2) Rasch analysis; 3) reliability analysis; and, 4) feasibility analysis. Exploratory factor analysis and Rasch analysis were conducted to examine the internal construct validity of the SOS-Aphasia. One of the key assumptions of the Rasch model, discussed in more detail below, is that items on a scale represent the same latent construct. A latent construct is an underlying ability that cannot be directly measured, but can be inferred through performance, such as in responses to a test or questionnaire (e.g., inferring level of third-party functioning and third-party disability based on responses to items on the SOS-Aphasia) (Bond & Fox, 2012). When items on a scale measure the same latent construct, they are considered to be unidimensional. Previous qualitative research has revealed the multi-faceted nature of third-party functioning and third-party disability (Grawburg et al., 2013b, 2013c); therefore, it was projected that that the SOS-Aphasia would be multi-dimensional, in that the items would reflect more than one latent construct. Thus, exploratory factor analysis was conducted prior to Rasch analysis to examine the underlying structure of the SOS-Aphasia and identify domains of third-party functioning and third-party disability.

#### *6.3.3.1 Exploratory Factor Analysis*

As part of the examination of the dimensionality of the SOS-Aphasia, exploratory factor analysis was used to identify the number of latent constructs and group items into factors. Principal component analysis (PCA) was conducted on a polychoric matrix to provide an estimation of the normal distribution between ordinal variables on the scale (Holgado-Tello, Chacón–Moscoso, Barbero–García, & Vila-Abad, 2012). The data were determined to be suitable for factor analysis based on: i) a significant value for Bartlett's test of sphericity (Bartlett, 1954); ii) the Kaiser-Meyer-Olkin measure of sampling adequacy >0.6 (Kaiser, 1970; Kaiser, 1974); and, iii) multiple coefficients ≥0.3 in the correlation matrix (Tabachnick & Fidell, 2013).

Factor retention, or identification of the number of underlying constructs, was based upon:

a) *Kaiser's criterion*. Retain factors with eigenvalues equal to or greater than 1.0 (Kaiser, 1960).

b) *Scree plot*. Examination of the scree plot to identify and retain eigenvalues with the greatest magnitude (i.e., omit factors with eigenvalues judged to be insignificant based on the visual inspection of the graph of component number and eigenvalue) (Cattell, 1966).

c) *Parallel analysis*. Parallel analysis to retain only the factors with eigenvalues greater than randomly generated eigenvalues that would have resulted from the same sample size and number of participants (Horn, 1965).

d) *The minimum average partial (MAP) test*. The MAP test retains factors based on a greater proportion of systematic variance compared to unsystematic variance through PCA and subsequent analysis of partial correlation matrices (Velicer, 1976).

Factor interpretability can be improved through orthogonal or oblique rotation of the matrix. Though orthogonal rotation is usually more easily interpreted, oblique rotation is appropriate when the factors are correlated (Tabachnick & Fiddell, 2013). Exploration of both methods is recommended in order to produce the most

interpretable solution (Fabrigar & Wegener, 2011). Following rotation, items are grouped into factors based on an item-factor loading value (a value ≥.32), which is selected based on the data in consideration of cross-loading items and low loading items (Tabachnick & Fiddell, 2013). Subsequently, each factor underwent separate Rasch analysis.

#### *6.3.3.2 Rasch Analysis*

Item response theory (IRT) is an approach for the development and psychometric analysis of scales (Velozo, et al., 2012). The Rasch measurement model, an example of an IRT model, is an increasingly used method for establishing the internal construct validity of clinical scales, particularly in rehabilitation (Velozo, et al., 2012). This type of analysis involves testing the fit of the data to the assumptions of the Rasch model. One assumption of the Rasch model is that items on the scale are unidimensional in that they measure only one underlying trait or attribute (Baylor, et al., 2011). For example, a room can be measured either by its size or temperature, but if these measures were combined as a size-temperature value, they would confound one another and be difficult to interpret. A second assumption of the Rasch model is that of local independence, which means that response to one item should not be related to the response on a different item. For example, if two or more questions on a reading comprehension test are based on the same paragraph, comprehension of the paragraph may influence responses to both questions violating the assumption of local independence (Baylor, et al., 2011). The Rasch model is considered a 1-parameter IRT model because only one item parameter (i.e., item difficulty) is permitted to vary and interact with the underlying trait (i.e., person ability), while other parameters (i.e., item discrimination and pseudochance/guessing) are assumed to be constant among items (Harris, 1989).

In Rasch terms, “person ability” is used to describe a respondent’s level of the underlying trait (e.g., the person’s level of third-party functioning and third-party disability). “Item difficulty” describes the location of the item on the logit scale where the highest and lowest categories have equal probability of being endorsed (e.g., the level third-party functioning and third-party disability portrayed by the SOS-Aphasia item) (Bond & Fox, 2012). The Rasch model describes the probability of a certain

response as a logistic function of the difference between the person ability and the item difficulty (Tennant & Conaghan, 2007). Through Rasch analysis, person ability and item difficulty are log transformed and calibrated along the same equal-interval scale, called a logit scale (Bond & Fox, 2012). Logits, or log odd units, can be thought of as units of measure on a ruler that increase as the items become more difficult to endorse. In other words, endorsement of an item with a higher logit value indicates a greater level of ability. In the case of the SOS-Aphasia, selecting a response category associated with a higher logit value indicates greater third-party functioning, while response categories lower on the logit scale are associated with greater third-party disability.

The 1-parameter Rasch model was selected for this study in order to develop sample-free items and derive interval-level scores from categorical data (i.e., Likert scales) (Velozo et al., 2012). Due to the Likert-style response scale used in the SOS-Aphasia, a polytomous version of the Rasch model was required to explain the relationship between the person's underlying ability and the probability of selecting a particular response category (Tennant & Conaghan, 2007). In polytomous Rasch models, category thresholds occur on the location where an individual with that level of ability (or latent trait) has a 50% chance of endorsing one of two neighbouring categories (Bond & Fox, 2012). For example, an SOS-Aphasia category threshold would occur when a family member's level of third-party functioning and third-party disability rests on the logit value between the two categories "mild problem" and "moderate problem", suggesting they are just as likely to endorse either category. From the polytomous versions of the Rasch model, the Rasch partial credit model was selected to allow for variation in the order and distance between the 7-point rating scale categories in each item and to explore the need for changes to the rating scale (Tennant & Conaghan, 2007). Rasch analysis of each of the factors identified through exploratory factor analysis above was conducted with Winsteps version 3.73 (Linacre, 2012).

Fit of the data to the Rasch model was assessed based on: a) appropriateness of the rating scale, b) unidimensionality, c) local independence, d) test targeting, e) person reliability, and f) differential item functioning (DIF).

a) *Appropriateness of the rating scale*. The category structure of the 7-point rating scale was evaluated based on summary statistics and visual examination of the category response curves. Based on the statistics generated in Winsteps, the categories were considered appropriate when: i) there was a sufficient number of cases (e.g., 10 per category); ii) average measures increased monotonically across categories; iii) good category fit was demonstrated (e.g., outfit mean square values of <2.0); and, iv) no disordered step calibrations were observed (i.e., difficulty increased as steps increased) (Linacre, 2002). Visual examination of the category response curves provided additional information about the distribution of each response category. Namely, each category should cover a sufficient distribution on the category probability curves where it is the most likely response option, and have a peak that is unique from the other categories (Bond & Fox, 2012). The original scoring of the 7 response categories can be represented as '0 complete problem', '1 moderate-severe problem', '2 mild problem', '3 no change', '4 mild positive change', '5 moderate positive change', and '6 complete positive change', or 0123456. When problematic rating scale performance was identified, response categories were collapsed for rating scale optimization based on joint consideration of theoretical and clinical relevance (Bond & Fox, 2012).

b) *Unidimensionality*. Each SOS-Aphasia factor was tested to confirm that only one latent construct accounted for the common variance by conducting a Rasch-based PCA of the residual and examining the goodness of fit statistics (described below). The same analysis was also conducted with all items from the SOS-Aphasia subscales together to determine if a summary score could be derived. In Rasch-based PCA of residuals, >50% of the total variance should be explained by the Rasch-derived measure (Linacre, 2013). In addition, residual variance after the Rasch measure was removed should be randomly distributed, as demonstrated by an eigenvalue of <2.0 in the second largest construct (Linacre, 2013).

   Consideration of item and person fit is also important in the assessment of unidimensionality. Acceptable fit statistics demonstrate that item difficulty or

person ability fit the model's hierarchical expectations, providing evidence for test unidimensionality and person response validity (Chien & Bond, 2009). Goodness of fit statistics provide an indication of the observed responses compared to those expected by the model, or how well items fit the latent construct (Bond & Fox, 2012). Two types of goodness of fit statistics are infit and outfit statistics, which are determined by calculating the mean square (MnSq) of the residual difference between the observed and expected responses. Infit statistics (infit MnSq) give more weight to responses of individuals whose ability level is near the item difficulty level; outfit statistics (outfit MnSq) are more sensitive to outliers (Bond & Fox, 2012). Infit and outfit statistics are transformed based on sample size to become normally distributed Z-standardized statistics (Zstd). Zstd are used to test the null hypothesis that the data fit the model perfectly (Bond & Fox, 2012). In this study, persons with extremely misfit values (i.e., infit and outfit MnSq ≥2.0 and Zstd ≥2.0 indicating 100% departure from the expectations of the Rasch model) were omitted if the result was improved unidimensionality of the scale. Items with MnSq >1.4 and Zstd >2.0 were also considered misfit and removed from the SOS-Aphasia if removal resulted in improved unidimensionality and was also supported clinically (Bond & Fox, 2012). Chi-square analysis was used to identify statistically significant differences in the characteristics of extremely misfit and well-fit persons.

c) *Local independence*. The Rasch assumption of local independence presumes that, besides the latent construct identified through Rasch analysis, the scale items are not related. If two items are locally dependent, endorsement of one item leads to endorsement of the other. Local dependence is demonstrated when correlations between the residuals (i.e., correlations between items after the Rasch-derived measure is removed) are >.7 (Linacre, 2013). Evidence of unidimensionality also supports the assumption of local independence (Tennant & Conaghan, 2007).

d) *Test targeting*. Test targeting is an indication of the appropriateness of the item difficulty levels for the sample (Tennant & Conaghan, 2007). Within each subscale, items on the SOS-Aphasia were expressed as logits,

representing linear interval-level measures, and calibrated in hierarchical order from easiest to most difficult on the item-person map. Similarly, person scores were transformed to logits and expressed along the same scale. Visual inspection of the item-person map allowed examination of how well the items cover the range of third-party functioning and third-party disability in family members of people with aphasia in this sample (Bond & Fox, 2012). The item-person map of each subscale was checked for problems with test targeting, including: i) floor and ceiling effects, ii) item redundancy, iii) gaps between item categories, and iv) mismatch between the mean person ability and item difficulty. Floor effects are observed when a large proportion of the respondents have a person ability level lower than the lowest item difficulty. Ceiling effects occur when a large proportion of respondents have a person ability higher than the range of test item difficulty. For example, in the case of a ceiling effect, people with different levels of the underlying trait would have the same test score (i.e., the maximum score), but because more difficult items were not included in the test, it would be impossible to differentiate between them. Item redundancy occurs when two items have the same item location, or logit value, representing the same level of the underlying trait. Redundant items may be deleted to reduce the number of test items, thereby reducing the response burden while still providing the same amount of information regarding the underlying trait. In the case of polytomous items, the response thresholds for each response category should be evenly spread, without gaps, along the logit scale in order to adequately differentiate between persons with different abilities and for more accurate indication of change. Items gaps >.5 logits are considered substantial (Lai & Eton, 2002). In addition, the mean person ability and mean item difficulty should be approximately equal.

e) *Reliability*. Reliability testing provides an indication of the reproducibility of the observed responses (e.g., that people with high level responses actually do have high levels of the underlying trait) (Linacre, 2013). In Rasch analysis, a person reliability coefficient >.70 indicates good internal consistency (Bond & Fox, 2012).

f) *Differential Item Functioning (DIF)*. DIF, or item bias, is an indicator of the

instability of item responses across participants groups with different characteristics. DIF is present when people with the same level of ability and from different groups (e.g., males and females) demonstrate different response probabilities for a certain item. DIF analysis was conducted if there were theoretical reasons to suspect item response bias and sufficient persons with the characteristic of interest (i.e., ≥30 per category) (Linacre, 1994). DIF was identified when the magnitude of the differences in Rasch-based item difficulty calibrations between groups were >0.5 logits (Bond & Fox, 2012) and there was a significant difference in the item difficulty calibrations using paired t-tests ($p<0.05$) (Tennant, et al., 2004). Bonferonni adjustment is sometimes used to adjust p-values when multiple t-tests are conducted (e.g., DIF analysis) because large sample sizes can overestimate significance (Portney & Watkins, 2009). With the moderate sample size of 104 family members in this study, Bonferonni adjustment was not used, as it would make it more difficult to detect DIF items.

#### *6.3.3.3 Feasibility*

Measuring feasibility is important for establishing the practicality and relevance of using a particular scale (Bowen, et al., 2009). Feasibility was assessed through examination of the length of time to complete the SOS-Aphasia, completion rates of individual items, and ability to self-administer. In this study, completion time was recorded when family members completed the scale online.

#### *6.3.3.4 Test-retest reliability*

Test-retest reliability of the SOS-Aphasia was examined to assess the temporal stability of the responses. The weighted kappa ($w\kappa$) statistic was used for examining test-retest reliability of individual items. Strength of agreement was interpreted as slight $w\kappa$=0-0.20, fair $w\kappa$=0.21-0.40, moderate $w\kappa$=0.41-0.60, good $w\kappa$=0.61-0.80, and very good $w\kappa$=0.81-1.00 (Landis & Koch, 1977). Factors scores, generated through Rasch analysis, from the initial and retest were compared using the intraclass

correlation coefficient (ICC), which is interpreted in the same way as wκ (Deyo, Diehr, & Patrick, 1991).

## 6.4 RESULTS

### 6.4.1 Sample details

Of the 132 family members identified for participation in the study, 104 completed the SOS-Aphasia and demographics form yielding a 78.7% response rate. Of the 70 people with aphasia identified for participation in the study, 60 were included. Ten additional people with aphasia volunteered to participate, but were excluded as three were extremely unwell, two had dementia, and five did not have family members who were willing to participate. Because these 10 potential participants with aphasia were excluded before contact with family members occurred, the number of family members excluded based on the person with aphasia's circumstances is unknown. Table 6.2 displays the participant characteristics.

Table 6.2.

*Participant characteristics*.

| | Mean (SD) | Range | Frequency |
|---|---|---|---|
| **FM details** | | | |
| Female | | | 79 (76%) |
| Male | | | 25 (24%) |
| Age (years) | 54.9 (17.2) | 12-86 | |
| Relationship to PWA | | | |
| Spouse/partner | | | 44 (42.3%) |
| Child | | | 38 (36.5%) |
| Sibling | | | 7 (6.7%) |
| Parent | | | 7 (6.7%) |
| Other | | | 7 (6.7%) |
| Live with PWA | | | 53 (51%) |
| Ethnicity | | | |
| New Zealander | | | 59 (56.7)% |
| Mãori | | | 7 (6.7%) |
| Australian | | | 24 (23.1%) |
| European | | | 9 (8.7%) |
| Asian | | | 4 (3.9%) |
| Not stated | | | 1 (<1%) |
| **PWA details** | | | |
| Female | | | 21 (35%) |
| Male | | | 39 (65%) |
| Age (years) | 68.3 (11.4) | 36-88 | |
| Time post-onset (years) | 4.4 (3.5) | .25-17.5 | |
| AQ* | 62.8 (32.5) | 6.7-99.8 | |
| BOSS† | 32 (10.4) | 6.6-53.5 | |

FM=family member; PWA=person with aphasia.

*Aphasia Quotient= Summary score on the Western Aphasia Battery-Revised, indicating level of aphasia severity; possible score=0-100; lower score=greater severity.

†Burden of Stroke Scale score, indicating level of stroke-related difficulties; possible score 0-100; higher scores=greater severity.

### 6.4.2 Results of factor analysis

SPSS 19.0 for Mac (IBM Corp., 2010) and R (Team, 2010) were used for factor analysis procedures. The factorability of the data was confirmed as Bartlett's test of sphericity was highly significant (p=0.000), the Kaiser-Meyer-Olkin measure of sampling adequacy value of 0.705 was adequate, and the correlation matrix revealed many correlations ≥0.3 between variables.

The following results provided evidence for the number of factors to retain:

a) *Kaiser's criterion.* PCA of the 34-item SOS-Aphasia revealed eight factors with eigenvalues >1.0 explaining 70.38% of the variance.
b) *Scree plot*. Inspection of the scree plot (displayed in figure 6.1) provided evidence for seven factors.
c) *Parallel analysis*. Parallel analysis resulted in five factors with eigenvalues greater than those occurring based on a randomly generated correlation matrix of the same size.
d) *MAP test*. The MAP test showed that six factors contained proportionally more systematic than unsystematic variance. Further inspection of the MAP test results revealed close average squared correlations for both five and six factor solutions (O'Connor, 2000).

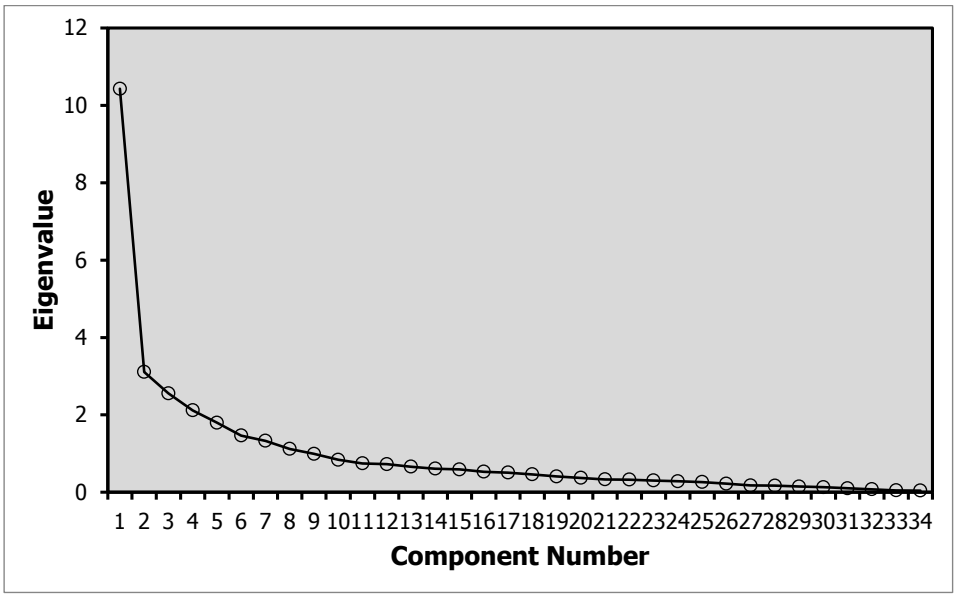


Figure 6.1. Scree plot of eigenvalues based on exploratory factor analysis of the original 34-item SOS-Aphasia. This plot is not conclusive, but change in the slope before the 8th component provides evidence for retention of 7 components.

Based on these results, potential solutions with five, six, seven, and eight factors were explored with oblique and orthogonal rotation to examine factor interpretability. PCA of the 5 factor model, conducted with oblique rotation (oblim, delta = 0), produced the best solution and allowed for the modest correlation (r=0.32) between two of the factors (Fabrigar & Wegener, 2011; Tabachnick & Fiddell, 2013). An item-factor loading cut-off of 0.5 produced the cleanest factor structure (i.e., at least three items loaded onto each factor and no items cross loaded) and interpretable factors (Costello & Osborne, 2005; Devellis, 2012). The five retained factors explained 58.86% of the variance. Respectively, factors 1 through 5 explained 30.69%, 9.15%, 7.52%, 6.23%, and 5.29% of the variance. Eight items that did not correlate highly (i.e., ≥0.5) with any factor were omitted from the final solution. The five factor model demonstrated conceptually meaningful constructs relative to the earlier qualitative research results and were labelled: Factor 1 – Health and daily life (9 items); Factor 2 – Attitude and personal life (3 items); Factor 3 – Helping others (4 items); Factor 4 – Communication and emotions (6 items); Factor 5 – Outside influences and interactions (4 items). All items that correlated highly with the factor were retained for Rasch analysis. Table 6.3 displays the factor loadings.

Table 6.3

*Item-factor loadings for the 5 factor direct oblim rotation of the 34-item SOS-Aphasia (n=104).*

| Item | Factor 1 Health & daily life | Factor 2 Attitude & personal life | Factor 3 Helping others | Factor 4 Communication & emotions | Factor 5 Outside influences & interactions |
|---|---|---|---|---|---|
| 30. Paid or volunteer work | **.802*** | -.177 | -.143 | .254 | -.020 |
| 29. Finances | **.800*** | .066 | -.118 | .037 | -.093 |
| 15. Care for other FMs | **.719*** | -.026 | .044 | -.133 | .084 |
| 28. Social activities | **.667*** | -.320 | -.306 | -.065 | .298 |
| 2. Health | **.642*** | .192 | -.039 | -.105 | -.108 |
| 27. Recreational activities | **.610*** | -.187 | -.255 | -.102 | .106 |
| 3. Physical functioning | **.579*** | .067 | -.214 | -.221 | -.021 |
| 5. Stressed | **.503*** | .027 | .126 | -.498 | .023 |
| 9. Emotional | **.500*** | .130 | .132 | -.304 | .112 |

| | | | | | |
|---|---|---|---|---|---|
| 14. Chores | .499 | .212 | -.089 | -.198 | -.200 |
| 17. Administrative tasks | .409 | .159 | -.397 | -.118 | -.108 |
| 34. Personal changes | -.042 | **.831*** | .054 | .129 | -.082 |
| 33. Attitude | .085 | **.776*** | .009 | .154 | .137 |
| 10. Appreciative | -.038 | **.622*** | -.334 | .038 | .263 |
| 23. Speech therapy | .085 | .060 | **-.738*** | -.125 | .054 |
| 24. Explain aphasia | .066 | .041 | **-.731*** | .037 | .305 |
| 31. Volunteer with PWA | .165 | -.048 | **-.576*** | .195 | -.111 |
| 20. Source of social contact | .194 | .042 | **-.545*** | -.314 | .040 |
| 21. Help PWA socialize | .136 | -.104 | -.494 | -.416 | -.047 |
| 12. Relationship with PWA | -.139 | .338 | -.413 | -.411 | .009 |
| 25. Relationship with relatives | .206 | .103 | -.330 | -.127 | -.183 |
| 19. New way to communicate with PWA | -.018 | -.218 | -.127 | **-.801*** | -.024 |
| 18. Ease of communication with PWA | .085 | -.299 | -.175 | **-.699*** | .033 |

| | | | | | |
|---|---|---|---|---|---|
| 1. Overall | .165 | .021 | -.007 | **-.666*** | -.052 |
| 22. Help PWA communicate | .032 | -.068 | -.363 | **-.603*** | .005 |
| 6. Worried | .450 | .125 | .215 | **-.579*** | .042 |
| 4. Sad | .349 | .098 | .217 | **-.573*** | .048 |
| 13. Physical intimacy | -.113 | .317 | -.397 | -.437 | -.320 |
| 16. Caregiver | .142 | .195 | .058 | -.433 | .329 |
| 26. Friendships | -.036 | .002 | -.081 | -.074 | **.792*** |
| 32. Education/learning | .121 | .278 | .027 | .379 | **.660*** |
| 11. Focus, memory, decision-making | .444 | .225 | .012 | -.041 | **-.501*** |
| 8. Frustrated, angry, annoyed | .331 | .183 | .328 | -.322 | **.501*** |
| 7. Embarrassed/proud | -.257 | .227 | -.237 | -.278 | .421 |

*Factor loadings ≥0.5.

### 6.4.3 Results of Rasch Analysis

**a)** *Appropriateness of the rating scale*. Rasch analysis of the 7-point rating scale revealed that all items did not fulfil at least one of the four predetermined criteria [i.e., 26 items had at least one category with fewer than 10 cases per category, 6 had measures that did not increase monotonically (average measures were reversed or did not increase sequentially, as expected), 3 demonstrated category misfit, and 8 had disordered step calibrations]. Based on these findings and in consideration of clinical relevance, various collapsing options were trialled and two 5-point rescoring approaches were selected for optimizing the SOS-Aphasia rating scale. For factors 1, 3, 4, and 5, the five new response categories were '0 complete problem', '1 moderate-severe problem', '2 mild problem', '3 no change', and '4', a new category including all grades of 'positive change.' This rescoring can be represented as 0123444 (i.e., categories 4, 5, and 6 collapsed into 4, while categories 0, 1, 2, and 3 remained the same). Figure 6.2 displays an example of improved rating scale performance with 0123444 rescoring for item #9 (emotional). For factor 2, the five new response categories were '0', a new category encompassing all grades of 'problem', in addition to the existing categories of '1 no change', '2 mild positive change', '3 moderate positive change', '4 complete positive change.' This rescoring can be represented as 0001234 (i.e., categories 0, 1, 2 were collapsed into 0 and the rest of the categories re-numbered 1, 2, 3, 4). Figure 6.3 provides visual support for the improved rating scale performance with 0001234 rescoring for item #10 (appreciative). These 2 formats of 5-point ratings scales were used in subsequent analyses. The rating scale analyses are presented in Tables 6.4, 6.5, 6.6, and corresponding to the initial 7-point rating scale analysis, the interim 5-point rating scale analysis, and the final 5-point rating scale analysis with extremely misfit persons and misfit items removed. Misfit items and extremely misfit persons are described in the next section.

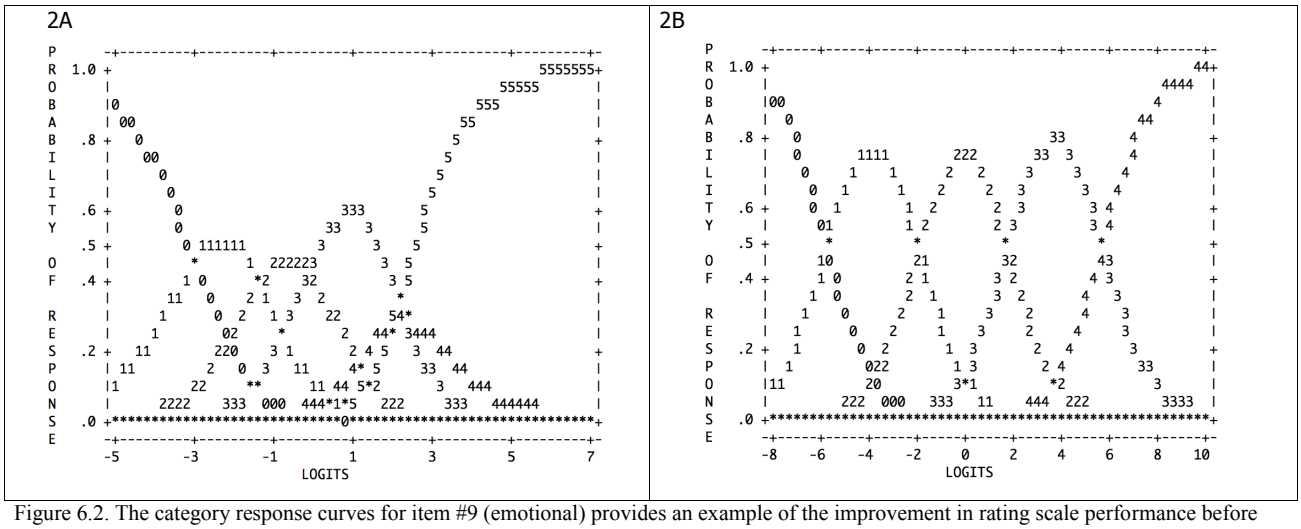


Figure 6.2. The category response curves for item #9 (emotional) provides an example of the improvement in rating scale performance before and after recoding. 6.2A displays the initial 7-point category response curve demonstrating that the category 4 is indistinct from categories 3 and 5. 6.2B displays the recoded 5-point category response curve where categories 4, 5, and 6 have been collapsed into one category. 6.2B shows that after recoding, each category has a distinct peak indicating that each category is a unique and separate from the other response categories. In 6.2A, 0=complete problem, 1=moderate-severe problem, 2=mild problem, 3=no problem, 4=mild positive change, 5=moderate positive change, and 6=complete positive change. In 2B, 0=complete problem, 1=moderate-severe problem, 2=mild problem, 3=no problem, and 4=new category covering mild, moderate, and complete positive change.

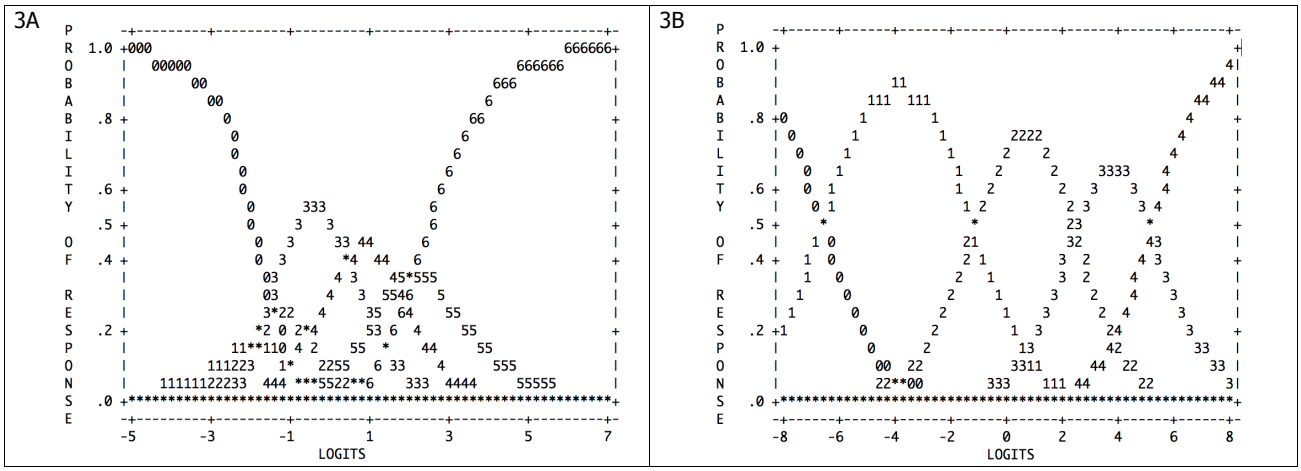


Figure 6.3. The category response curves for item #10 (appreciative) before and after recoding provides another example of the improvement in rating scale performance based on recoding of the more positively oriented items in factor 2. 6.3A displays the initial 7-point category response curve demonstrating that categories 1 and 2 are indistinct from categories 0 and 3. 3B displays the recoded 5-point category response curve where categories 0, 1, and 2 have been collapsed into one category. 6.3B shows that after recoding, each category has a distinct peak indicating that each category is a unique and separate from the other response categories. In 6.3A, 0=complete problem, 1=moderate-severe problem, 2=mild problem, 3=no problem, 4=mild positive change, 5=moderate positive change, and 6=complete positive change. In 6.3B, 0=new category representing complete problem, moderate-severe problem, and mild problem, 1=no change, 2=mild positive change, 3=moderate positive change, and 4=complete positive change.

Table 6.4.

*Analysis of the initial rating scale*.

| | Rating category | Category count (%) | Average measure | Outfit MnSq | Step Calibration |
|---|---|---|---|---|---|
| **Health & daily life** | | | | | |
| 2. Health | 0 | **2(2%)*** | -3.47 | .88 | - |
| | 1 | 12(12%) | -1.71 | .74 | -2.30 |
| | 2 | 25(24%) | -.24 | .47 | .38 |
| | 3 | 65(63%) | 1.80 | 1.09 | 1.91 |
| | 4 | **-*** | - | - | - |
| | 5 | **-*** | - | - | - |
| | 6 | **-*** | - | - | - |
| 3. Physical functioning | 0 | **1(1%)*** | -4.32 | .71 | - |
| | 1 | 13(13%) | -1.83 | .83 | -5.08 |
| | 2 | 32(31%) | -.19 | .46 | -1.52 |
| | 3 | 56(54%) | 2.01 | .76 | .65 |
| | 4 | **2(2%)*** | 2.42 | .91 | 5.95 |
| | 5 | **-*** | - | - | - |
| | 6 | **-*** | - | - | - |
| 5. Stressed | 0 | **5(5%)*** | -2.00 | 1.59 | - |
| | 1 | 23(22%) | -1.20 | .74 | -3.88 |
| | 2 | 44(42%) | .93 | .78 | -1.26 |
| | 3 | 27(26%) | 2.42 | .60 | 1.50 |
| | 4 | **5(5%)*** | 2.94 | 1.15 | 3.65 |
| | 5 | **-*** | - | - | - |
| | 6 | **-*** | - | - | - |

| | | | | | |
|---|---|---|---|---|---|
| 9. Emotional | 0 | **2(2%)*** | -3.35 | 1.14 | - |
| | 1 | 13(13%) | -1.48 | .81 | -4.95 |
| | 2 | 34(33%) | .05 | 1.17 | -2.31 |
| | 3 | 46(44%) | 1.95 | .84 | .08 |
| | 4 | **7(7%)*** | **1.74†** | 1.96 | 3.53 |
| | 5 | **2(2%)*** | 2.86 | 1.53 | 3.65 |
| | 6 | **-*** | - | - | - |
| 15. Care for other relatives | 0 | **7(7%)*** | -2.78 | .83 | - |
| | 1 | **7(7%)*** | -1.24 | .71 | -1.87 |
| | 2 | 24(23%) | .14 | 1.39 | **-1.95§** |
| | 3 | 55(53%) | 1.51 | 1.34 | -.02 |
| | 4 | 11(11%) | 2.28 | 1.15 | 3.84 |
| | 5 | **-*** | - | - | - |
| | 6 | **-*** | - | - | - |
| 27. Recreational activities | 0 | **6(6%)*** | -2.91 | .80 | - |
| | 1 | 12(12%) | -1.05 | 1.22 | -2.92 |
| | 2 | 34(33%) | .31 | .94 | -1.87 |
| | 3 | 47(45%) | 1.87 | .98 | .49 |
| | 4 | **5(5%)*** | 3.00 | .89 | 4.30 |
| | 5 | **-*** | - | - | - |
| | 6 | **-*** | - | - | - |
| 28. Social activities | 0 | **5(5%)*** | -3.29 | .57 | - |
| | 1 | 14(13%) | -1.36 | .44 | -3.18 |
| | 2 | 23(22%) | .13 | .87 | -1.31 |
| | 3 | 57(55%) | 1.88 | .78 | -.13 |
| | 4 | **5(5%)*** | **1.74†** | 1.15 | 4.61 |

| | | | | | |
|---|---|---|---|---|---|
| | 5 | **-*** | - | - | - |
| | 6 | **-*** | - | - | - |
| 29. Finances | 0 | **8(8%)*** | -2.60 | .81 | - |
| | 1 | 10(10%) | -1.49 | .43 | -2.75 |
| | 2 | 21(20%) | .00 | .43 | -2.11 |
| | 3 | 64(62%) | 1.83 | 1.03 | -.92 |
| | 4 | **1(1%)*** | 2.12 | .95 | 5.78 |
| | 5 | **-*** | - | - | - |
| | 6 | **-*** | - | - | - |
| 30. Paid or volunteer work | 0 | **4(4%)*** | -3.26 | 1.06 | - |
| | 1 | **7(7%)*** | -1.25 | 1.95 | -2.75 |
| | 2 | 21(20%) | -.19 | 1.21 | -2.00 |
| | 3 | 68(65%) | 1.49 | 1.28 | -.44 |
| | 4 | **4(4%)*** | 1.91 | 1.08 | 5.19 |
| | 5 | **-*** | - | - | - |
| | 6 | **-*** | - | - | - |
| **Attitude & personal life** | | | | | |
| 10. Appreciative | 0 | **1(1%)*** | -4.57 | .20 | - |
| | 1 | **1(1%)*** | -2.97 | 1.02 | **-2.88§** |
| | 2 | **5(5%)*** | -2.37 | .90 | -3.69 |
| | 3 | 30(29%) | -.38 | 1.35 | -2.52 |
| | 4 | 37(36%)* | .83 | 1.02 | .78 |
| | 5 | 20(19%) | 2.86 | .97 | 3.20 |
| | 6 | **9(9%)*** | 4.06 | 1.64 | 5.11 |
| 33. Attitude | 0 | **-** | - | - | - |

| | | | | | |
|---|---|---|---|---|---|
| | 1 | **1(1%)*** | -2.97 | 1.05 | - |
| | 2 | **2(2%)*** | -1.91 | 1.72 | -4.82 |
| | 3 | 33(32%) | -.47 | .56 | -3.03 |
| | 4 | 38(37%) | 1.45 | .86 | -.13 |
| | 5 | 18(17%) | 3.35 | .79 | 2.52 |
| | 6 | **3(3%)*** | 5.59 | .70 | 5.45 |
| 34. Personal changes | 0 | 1(1%)* | - | - | - |
| | 1 | 1(1%)* | **-1.28†** | **3.46‡** | - |
| | 2 | 7(7%)* | -3.01 | .48 | -5.15 |
| | 3 | 34(33%) | -.54 | .64 | -3.20 |
| | 4 | 34(33%) | 1.36 | .74 | .19 |
| | 5 | 24(23%) | 3.12 | 1.16 | 2.23 |
| | 6 | 3(3%)* | 4.49 | 1.26 | 5.93 |
| **Helping others** | | | | | |
| 20. Source of social contact | 0 | **5(5%)*** | -4.54 | 1.24 | - |
| | 1 | 13(13%) | -2.96 | 1.11 | -4.94 |
| | 2 | 22(21%) | -1.19 | 1.10 | -2.78 |
| | 3 | 46(44%) | -.02 | 1.04 | -1.54 |
| | 4 | 14(13%) | 1.36 | 1.07 | 1.88 |
| | 5 | **3(3%)*** | 1.84 | 1.97 | 3.50 |
| | 6 | **1(1%)*** | 4.11 | .25 | 3.89 |
| 23. Speech therapy | 0 | **2(2%)*** | -7.38 | .29 | - |
| | 1 | **7(7%)** | -3.78 | .82 | -6.18 |
| | 2 | 12(12%) | -2.45 | .88 | -2.87 |
| | 3 | 59(58%) | -.56 | .62 | -2.28 |
| | 4 | 16(16%) | 1.75 | .53 | 2.43 |

| | | | | | |
|---|---|---|---|---|---|
| | 5 | **4(4%)*** | 2.31 | .95 | 4.00 |
| | 6 | **1(1%)*** | 4.11 | .28 | 4.91 |
| 24. Explain aphasia | 0 | **1(1%)*** | - | - | - |
| | 1 | **2(2%)*** | -5.07 | .94 | - |
| | 2 | 32(31%) | -2.40 | .65 | -5.98 |
| | 3 | 23(22%) | -.74 | .72 | -.77 |
| | 4 | 35(34%) | .95 | .61 | -.08 |
| | 5 | **7(7%)*** | 1.22 | 2.85 | 3.25 |
| | 6 | **3(3%)*** | 2.95 | .95 | 3.57 |
| 31. Volunteer with PWA | 0 | **1(1%)*** | - | - | - |
| | 1 | **-*** | - | - | - |
| | 2 | **2(2%)*** | -1.95 | .87 | - |
| | 3 | 88(85%) | -.85 | 1.39 | -7.41 |
| | 4 | 11(11%) | 1.65 | .72 | 1.65 |
| | 5 | **-*** | - | .00 | - |
| | 6 | **1(1%)*** | 2.83 | 1.38 | 5.76 |
| **Communication & emotions** | | | | | |
| 1. Overall | 0 | **6(6%)*** | -5.29 | .76 | - |
| | 1 | 34(33%) | -2.51 | .74 | -5.91 |
| | 2 | 40(38%) | -.03 | .48 | -1.43 |
| | 3 | 12(12%) | .83 | .94 | 1.25 |
| | 4 | 8(8%)* | 1.37 | .68 | 1.12 |
| | 5 | **3(3%)*** | 1.79 | .69 | 2.22 |
| | 6 | **1(1%)*** | **.49†** | **4.83‡** | 2.75 |
| 4. Sad | 0 | **-*** | - | - | - |
| | 1 | 23(22%) | -3.56 | .96 | - |

| | | | | | |
|---|---|---|---|---|---|
| | 2 | 49(47%) | -.70 | .83 | -3.65 |
| | 3 | 22(21%) | .62 | .82 | -.09 |
| | 4 | **9(9%)*** | 1.13 | 1.40 | .91 |
| | 5 | **1(1%)*** | 2.32 | .59 | 2.83 |
| | 6 | **-*** | - | - | - |
| 6. Worried | 0 | **5(5%)*** | -4.76 | 1.34 | - |
| | 1 | 20(19%) | -3.16 | 1.03 | -4.75 |
| | 2 | 53(51%) | -.46 | .80 | -1.44 |
| | 3 | 22(21%) | .66 | 1.12 | 2.22 |
| | 4 | **4(4%)*** | 1.42 | 1.10 | 3.96 |
| | 5 | **-*** | - | - | - |
| | 6 | **-*** | - | - | - |
| 18. Ease of communication with PWA | 0 | 12(12%) | -4.50 | 1.06 | - |
| | 1 | 37(36%) | -1.60 | .96 | -4.75 |
| | 2 | 40(38%) | .15 | .70 | -1.16 |
| | 3 | 12(12%) | .83 | 1.02 | 1.30 |
| | 4 | **2(2%)*** | 2.23 | .23 | 2.60 |
| | 5 | **1(1%)*** | 2.32 | .51 | **2.01§** |
| | 6 | **-*** | - | - | - |
| 19. New way to communicate with PWA | 0 | 11(11%) | -4.29 | 1.59 | - |
| | 1 | 27(26%) | -2.07 | 1.02 | -4.56 |
| | 2 | 57(55%) | -.03 | .83 | -1.77 |
| | 3 | 4(4%)* | 1.18 | .70 | **2.98§** |
| | 4 | **3(3%)*** | 1.98 | .47 | 1.36 |
| | 5 | **2(2%)*** | **1.71†** | 1.57 | 1.99 |
| | 6 | **-*** | - | - | **-** |

| | | | | | |
|---|---|---|---|---|---|
| 22. Help PWA communicate | 0 | **7(7%)*** | -5.30 | .76 | - |
| | 1 | 13(13%) | -3.22 | 1.02 | -4.47 |
| | 2 | 47(45%) | -.76 | .92 | -2.64 |
| | 3 | 25(24%) | .49 | 1.25 | 1.12 |
| | 4 | 10(10%) | .87 | 1.59 | 2.33 |
| | 5 | **2(2%)*** | .96 | 1.62 | 3.66 |
| | 6 | **-*** | - | - | - |
| **Outside influences & interactions** | | | | | |
| 8. Frustrated, angry, annoyed | 0 | **2(2%)*** | -2.43 | .69 | - |
| | 1 | 19(18%) | -.89 | .75 | -3.77 |
| | 2 | 33(32%) | .17 | .73 | -.99 |
| | 3 | 40(39%) | .71 | .63 | .00 |
| | 4 | **7(7%)*** | 1.41 | .69 | **2.40§** |
| | 5 | **2(2%)*** | 2.24 | .44 | 2.36 |
| | 6 | **-*** | - | - | - |
| 11. Focus, memory, decision-making | 0 | **2(2%)*** | .71 | **4.18‡** | - |
| | 1 | **8(8%)*** | **-1.07†** | 1.28 | -2.97 |
| | 2 | 22(21%) | .03 | 1.08 | -1.49 |
| | 3 | 61(59%) | .37 | 1.49 | -.71 |
| | 4 | 8(8%)* | .95 | 1.03 | 2.87**§** |
| | 5 | **3(3%)*** | 1.12 | 1.00 | 2.30 |
| | 6 | **-*** | - | - | - |
| 26. Friendships | 0 | **3(3%)*** | -2.23 | .56 | - |
| | 1 | **3(3%)*** | -1.29 | .43 | **-2.11§** |
| | 2 | 22(21%) | -.25 | 1.06 | -3.05 |
| | 3 | 55(53%) | .39 | .71 | -1.14 |

| | | | | | |
|---|---|---|---|---|---|
| | 4 | 15(14%) | .87 | .86 | 1.61 |
| | 5 | **5(5%)*** | 1.32 | 1.40 | 1.88 |
| | 6 | **1(1%)*** | 1.69 | .35 | 2.80 |
| 32. Education/learning | 0 | **1(1%)*** | -2.66 | .27 | - |
| | 1 | **1(1%)*** | -2.16 | .08 | -1.95 |
| | 2 | **4(4%)*** | -1.06 | .85 | **-2.56§** |
| | 3 | 49(47%) | .00 | .92 | **-2.52§** |
| | 4 | 36(35%) | .59 | 1.05 | 1.09 |
| | 5 | 11(11%) | 1.07 | 1.16 | 2.48 |
| | 6 | **2(2%)*** | 1.50 | .51 | 3.46 |

Indications of a rating scale problem: *<10 cases per category; †reversed average measures; ‡ category misfit; §disordered step calibrations.

Table 6.5.

*Analysis of the rating scale after rescoring with 5-point rating scale*.

| | Rating category | Category count (%) | Average measure | Outfit MnSq | Step Calibration |
|---|---|---|---|---|---|
| **Health & daily life** | | | | | |
| 2. Health | 0 | **2(2%)*** | -3.37 | .88 | - |
| | 1 | 12(12%) | -1.62 | .74 | -2.30 |
| | 2 | 25(24%) | -.14 | .47 | .38 |
| | 3 | 65(63%) | 1.92 | 1.09 | 1.92 |
| | 4 | **-*** | - | - | - |
| 3. Physical functioning | 0 | **1(1%)*** | -4.22 | .71 | - |
| | 1 | 13(13%) | -1.73 | .83 | -5.09 |
| | 2 | 32(31%) | -.10 | .45 | -1.54 |
| | 3 | 56(54%) | 2.14 | .76 | .64 |
| | 4 | **2(2%)*** | 2.60 | .87 | 5.98 |
| 5. Stressed | 0 | **5(5%)*** | -1.90 | 1.59 | - |
| | 1 | 23(22%) | -1.11 | .74 | -3.90 |
| | 2 | 44(42%) | 1.04 | .79 | -1.28 |
| | 3 | 27(26%) | 2.55 | .64 | 1.50 |
| | 4 | **5(5%)*** | 3.06 | 1.18 | 3.68 |
| 9. Emotional | 0 | **2(2%)*** | -3.25 | 1.14 | - |
| | 1 | 13(13%) | -1.38 | .81 | -4.00 |
| | 2 | 34(33%) | .15 | 1.14 | -1.36 |
| | 3 | 46(44%) | 2.08 | .84 | 1.04 |
| | 4 | **9(9%)*** | 2.05† | 1.59 | 4.31 |
| 15. Care for other relatives | 0 | **7(7%)*** | -2.68 | .83 | - |

| | | | | | |
|---|---|---|---|---|---|
| | 1 | **7(7%)*** | -1.14 | .71 | -1.88 |
| | 2 | 24(23%) | .24 | 1.41 | -1.96 |
| | 3 | 55(53%) | 1.63 | 1.32 | -.03 |
| | 4 | 11(11%) | 2.38 | 1.17 | 3.87 |
| 27. Recreational activities | 0 | **6(6%)*** | -2.18 | .80 | - |
| | 1 | 12(12%) | -.95 | 1.23 | -2.93 |
| | 2 | 34(33%) | .40 | .94 | -1.89 |
| | 3 | 47(45%) | 2.00 | .98 | .49 |
| | 4 | **5(5%)*** | 3.14 | .89 | 4.33 |
| 28. Social activities | 0 | **5(5%)*** | -3.20 | .57 | - |
| | 1 | 14(13%) | -1.26 | .44 | -3.18 |
| | 2 | 23(22%) | .21 | .87 | -1.31 |
| | 3 | 57(55%) | 2.00 | .78 | -.13 |
| | 4 | **5(5%)*** | **1.88†** | 1.15 | 4.61 |
| 29. Finances | 0 | **8(8%)*** | -2.51 | .81 | - |
| | 1 | 10(10%) | -1.39 | .43 | -2.76 |
| | 2 | 21(20%) | .08 | .41 | -2.12 |
| | 3 | 64(62%) | 1.95 | 1.03 | -.93 |
| | 4 | **1(1%)*** | 2.24 | .93 | 5.81 |
| 30. Paid or volunteer work | 0 | **4(4%)*** | -3.17 | 1.06 | - |
| | 1 | **7(7%)*** | -1.20 | 1.55 | -2.76 |
| | 2 | 21(20%) | -.09 | 1.23 | -2.02 |
| | 3 | 68(65%) | 1.61 | 1.27 | -.45 |
| | 4 | **4(4%)*** | 2.04 | 1.09 | 5.23 |
| **Attitude & personal life** | | | | | |
| 10. Appreciative | 0 | **7(7%)*** | -3.30 | 1.03 | - |
| | 1 | 30(29%) | -1.78 | 1.39 | -4.25 |

| | | | | | |
|---|---|---|---|---|---|
| | 2 | 37(36%) | -.48 | 1.00 | -.81 |
| | 3 | 20(19%) | 1.51 | .96 | 1.59 |
| | 4 | **9(9%)*** | 2.69 | 1.62 | 3.47 |
| 33. Attitude | 0 | 12(12%) | -2.74 | 1.59 | - |
| | 1 | 33(32%) | -1.86 | .60 | -4.24 |
| | 2 | 38(37%) | .13 | .78 | -1.30 |
| | 3 | 18(17%) | 1.99 | .78 | 1.32 |
| | 4 | **3(3%)*** | 4.20 | .70 | 4.22 |
| 34. Personal changes | 0 | **9(9%)*** | -3.43 | .96 | - |
| | 1 | 34(33%) | -1.92 | .66 | -4.61 |
| | 2 | 34(33%) | .03 | .72 | -1.03 |
| | 3 | 24(23%) | 1.76 | 1.16 | .99 |
| | 4 | **3(3%)*** | 3.12 | 1.25 | 4.65 |
| **Helping others** | | | | | |
| 20. Source of social contact | 0 | **5(5%)*** | -3.00 | 1.26 | - |
| | 1 | 13(13%) | -1.51 | 1.20 | -3.21 |
| | 2 | 22(21%) | .43 | 1.32 | -1.04 |
| | 3 | 46(44%) | 1.74 | .92 | .30 |
| | 4 | 18(17%) | 3.88 | 1.26 | 3.96 |
| 23. Speech therapy | 0 | **5(5%)*** | -2.37 | 1.26 | - |
| | 1 | 13(13%) | -.88 | 1.22 | -3.23 |
| | 2 | 22(21%) | .97 | 1.04 | -1.06 |
| | 3 | 46(44%) | 2.42 | 1.15 | .28 |
| | 4 | 18(17%) | 3.90 | 1.29 | 4.02 |
| 24. Explain aphasia | 0 | **1(1%)*** | - | - | - |
| | 1 | **2(2%)*** | -3.53 | .95 | - |
| | 2 | 32(31%) | -.85 | .58 | -3.77 |

| | | | | | |
|---|---|---|---|---|---|
| | 3 | 23(22%) | .95 | .49 | 1.50 |
| | 4 | 45(44%) | 3.11 | 1.23 | 2.26 |
| 31. Volunteer with PWA | 0 | **1(1%)*** | - | - | - |
| | 1 | **-*** | - | - | - |
| | 2 | **2(2%)*** | -.26 | .84 | - |
| | 3 | 88(85%) | .84 | 1.66 | -4.78 |
| | 4 | 12(12%) | 4.00 | .99 | 4.78 |
| **Communication & emotions** | | | | | |
| 1. Overall | 0 | **6(6%)*** | -4.64 | .76 | - |
| | 1 | 34(33%) | -1.84 | .72 | -4.64 |
| | 2 | 40(38%) | .65 | .46 | -.15 |
| | 3 | 12(12%) | 1.65 | .94 | 2.57 |
| | 4 | 12(12%) | 2.25 | 1.15 | **2.23§** |
| 4. Sad | 0 | **-*** | - | - | - |
| | 1 | 23(22%) | -2.91 | .95 | - |
| | 2 | 49(47%) | -.03 | .81 | -2.74 |
| | 3 | 22(21%) | 1.40 | .82 | .84 |
| | 4 | 10(10%) | 2.19 | 1.37 | 1.90 |
| 6. Worried | 0 | **5(5%)*** | -4.10 | 1.35 | - |
| | 1 | 20(19%) | -2.54 | .99 | -4.84 |
| | 2 | 53(51%) | .23 | .79 | -1.52 |
| | 3 | 22(21%) | 1.46 | 1.07 | 2.18 |
| | 4 | **4(4%)*** | 2.56 | 1.26 | 4.19 |
| 18. Ease of communication with PWA | 0 | 12(12%) | -3.85 | 1.06 | - |
| | 1 | 37(36%) | -.96 | .96 | -4.28 |
| | 2 | 40(38%) | .86 | .70 | -.67 |
| | 3 | 12(12%) | 1.60 | 1.04 | 1.86 |

| | | | | | |
|---|---|---|---|---|---|
| | 4 | **3(3%)*** | 3.79 | .36 | 3.10 |
| 19. New way to communicate with PWA | 0 | 11(11%) | -3.63 | 1.60 | - |
| | 1 | 27(26%) | -1.41 | 1.05 | -4.07 |
| | 2 | 57(55%) | .68 | .85 | -1.26 |
| | 3 | **4(4%)*** | 2.12 | .66 | 3.58 |
| | 4 | **5(5%)*** | 2.84 | 1.27 | **1.75§** |
| 22. Help PWA communicate | 0 | **7(7%)*** | -4.65 | .76 | - |
| | 1 | 13(13%) | -2.56 | 1.02 | -3.57 |
| | 2 | 47(45%) | -.09 | .90 | -1.73 |
| | 3 | 25(24%) | 1.33 | 1.59 | 2.05 |
| | 4 | 12(12%) | 1.60 | 1.63 | 3.24 |
| **Outside influences & interactions** | | | | | |
| 8. Frustrated, angry, annoyed | 0 | **2(2%)*** | -1.49 | .69 | - |
| | 1 | 19(18%) | -.10 | .53 | -3.25 |
| | 2 | 33(32%) | 1.25 | .84 | -.46 |
| | 3 | 40(39%) | 1.89 | .62 | .66 |
| | 4 | **9(9%)*** | 2.92 | .82 | 3.05 |
| 11. Focus, memory, decision-making | 0 | **2(2%)*** | .83 | **5.18‡** | - |
| | 1 | **8(8%)*** | **-.28†** | .96 | -2.41 |
| | 2 | 22(21%) | .99 | 1.23 | -.95 |
| | 3 | 61(59%) | 1.51 | 1.45 | -.07 |
| | 4 | 11(11%) | 2.37 | 1.02 | 3.44 |
| 26. Friendships | 0 | **3(3%)*** | -1.37 | .55 | - |
| | 1 | **3(3%)*** | -.99 | .43 | **-.94§** |
| | 2 | 22(21%) | .84 | 1.17 | -1.90 |
| | 3 | 55(53%) | 1.51 | .71 | .10 |
| | 4 | 21(20%) | 2.16 | 1.11 | 2.74 |

| | | | | | |
|---|---|---|---|---|---|
| 32. Education/learning | 0 | **1(1%)*** | -2.14 | .26 | - |
| | 1 | **1(1%)*** | -1.80 | .07 | -.44 |
| | 2 | **4(4%)*** | -.37 | .67 | **-1.06§** |
| | 3 | 49(47%) | 1.12 | 1.20 | **-1.00§** |
| | 4 | 49(47%) | 1.84 | 1.10 | 2.50 |

Indications of a rating scale problem: *<10 cases per category; †reversed average measures; ‡ category misfit; §disordered step calibrations.

Table 6.6.

*Analysis of the 5-point rating scale with misfit persons and items removed*.

| | Rating category | Category count (%) | Average measure | Outfit MnSq | Step Calibration |
|---|---|---|---|---|---|
| **Health & daily life** | | | | | |
| 2. Health | 0 | **2(2%)*** | -3.83 | 1.14 | - |
| | 1 | **9(9%)** | -2.38 | .81 | -2.69 |
| | 2 | 25(26%) | .10 | .58 | -.06 |
| | 3 | 61(63%) | 3.07 | .98 | 2.75 |
| | 4 | **-*** | - | - | - |
| 3. Physical functioning | 0 | **1(1%)*** | -4.89 | .76 | - |
| | 1 | 12(12%) | -2.10 | 1.07 | -6.07 |
| | 2 | 28(29%) | -.06 | .32 | -1.94 |
| | 3 | 54(56%) | 3.35 | .61 | .97 |
| | 4 | **2(2%)*** | 3.84 | .76 | 7.03 |
| 5. Stressed | 0 | **3(3%)*** | -2.96 | 1.52 | - |
| | 1 | 21(22%) | -1.28 | .87 | -5.54 |
| | 2 | 43(44%) | 1.80 | .75 | -1.53 |
| | 3 | 26(27%) | 3.84 | .70 | 2.17 |
| | 4 | **4(4%)*** | 4.79 | 1.44 | 4.90 |
| 9. Emotional | 0 | **1(1%)*** | -5.58 | .40 | - |
| | 1 | 11(11%) | -1.76 | 1.08 | -5.71 |
| | 2 | 34(35%) | .53 | 1.12 | -1.86 |
| | 3 | 44(45%) | 3.22 | 1.06 | 1.80 |
| | 4 | **7(7%)*** | 3.64 | 1.49 | 5.76 |

| | | | | | |
|---|---|---|---|---|---|
| 27. Recreational activities | 0 | **6(6%)*** | -3.33 | 1.19 | - |
| | 1 | 11(11%) | -1.39 | .57 | -3.79 |
| | 2 | 30(31%) | .96 | 1.01 | -2.20 |
| | 3 | 45(46%) | 3.21 | .92 | .81 |
| | 4 | **5(5%)*** | 4.44 | 1.03 | 5.18 |
| 28. Social activities | 0 | **5(5%)*** | -3.70 | .73 | - |
| | 1 | 12(12%) | -1.45 | .55 | -4.01 |
| | 2 | 21(22%) | .38 | .65 | -1.81 |
| | 3 | 55(57%) | 3.18 | .82 | .10 |
| | 4 | **4(4%)*** | 3.43 | 1.22 | 5.72 |
| 29. Finances | 0 | **7(7%)*** | -3.21 | .98 | - |
| | 1 | 9(9%)* | -1.76 | .46 | -1.40 |
| | 2 | 19(20%) | .34 | .42 | -.22 |
| | 3 | 62(64%) | 3.10 | .82 | 1.62 |
| | 4 | -* | - | - | - |
| 30. Paid or volunteer work | 0 | **3(3%)*** | -4.42 | .64 | - |
| | 1 | **4(4%)*** | -2.06 | .85 | -3.54 |
| | 2 | 21(22%) | .13 | 1.69 | -3.19 |
| | 3 | 66(68%) | 2.59 | 1.58 | -.07 |
| | 4 | **3(3%)*** | 2.67 | 1.36 | 6.80 |
| **Attitude & personal life** | | | | | |
| 10. Appreciative | 0 | **5(5%)*** | -5.73 | .94 | - |
| | 1 | 29(31%) | -2.65 | 1.58 | -6.57 |
| | 2 | 36(38%) | -.51 | 1.28 | -1.12 |
| | 3 | 18(19%) | 2.56 | 1.09 | 2.49 |
| | 4 | **7(7%)*** | 4.78 | .71 | 5.21 |

| | | | | | |
|---|---|---|---|---|---|
| 33. Attitude | 0 | **8(8%)*** | -6.09 | .48 | - |
| | 1 | 30(31%) | -2.81 | .70 | -6.43 |
| | 2 | 38(40%) | .37 | .89 | -1.66 |
| | 3 | 17(18%) | 2.95 | 1.07 | 2.29 |
| | 4 | **3(3%)*** | 5.67 | .80 | 5.80 |
| 34. Personal changes | 0 | **9(9%)*** | -4.93 | 1.23 | - |
| | 1 | 32(33%) | -2.86 | .64 | -6.31 |
| | 2 | 32(33%) | .42 | .63 | -1.54 |
| | 3 | 21(22%) | 3.09 | 1.01 | 1.60 |
| | 4 | **2(2%)*** | 5.21 | 1.16 | 6.25 |
| **Helping others** | | | | | |
| 20. Source of social contact | 0 | **5(5%)*** | -2.73 | 1.45 | - |
| | 1 | 11(11%) | -1.63 | .37 | -3.48 |
| | 2 | 22(22%) | .91 | 1.24 | -1.55 |
| | 3 | 46(46%) | 2.67 | 1.24 | .33 |
| | 4 | 17(17%) | 4.57 | 1.37 | 4.70 |
| 23. Speech therapy | 0 | **2(2%)*** | -5.57 | .28 | - |
| | 1 | **6(6%)*** | -2.31 | .49 | -4.71 |
| | 2 | 11(11%) | -.81 | .70 | -1.15 |
| | 3 | 59(60%) | 1.88 | .57 | -.23 |
| | 4 | 20(20%) | 5.11 | .78 | 5.55 |
| 24. Explain aphasia | 0 | **1(1%)*** | - | - | - |
| | 1 | **2(2%)*** | -3.25 | 1.04 | - |
| | 2 | 31(31%) | -.53 | .57 | -4.09 |
| | 3 | 23(23%) | 1.68 | .66 | 1.42 |
| | 4 | 43(43%) | 4.03 | .74 | 2.68 |
| 31. Volunteer with PWA | 0 | **1(1%)*** | - | - | - |

| | | | | | |
|---|---|---|---|---|---|
| | 1 | **-*** | - | - | - |
| | 2 | **2(2%)*** | -.37 | .98 | - |
| | 3 | 87(87%) | 1.56 | 1.27 | -5.46 |
| | 4 | 10(10%) | 5.30 | .63 | 5.46 |
| **Communication & emotions** | | | | | |
| 1. Overall | 0 | **6(6%)*** | -5.51 | .75 | - |
| | 1 | 31(32%) | -2.55 | .69 | -5.37 |
| | 2 | 38(39%) | .71 | .52 | -.35 |
| | 3 | 11(11%) | 2.33 | .69 | 2.95 |
| | 4 | 12(12%) | 2.77 | 1.52 | **2.77§** |
| 4. Sad | 0 | **-*** | - | - | - |
| | 1 | 20(20%) | -4.15 | .76 | - |
| | 2 | 47(48%) | -.17 | .85 | -3.56 |
| | 3 | 22(22%) | 1.73 | .93 | .96 |
| | 4 | **9(9%)*** | 3.10 | .86 | 2.60 |
| 6. Worried | 0 | **5(5%)*** | -4.92 | 1.44 | - |
| | 1 | 18(18%) | -3.61 | .86 | -5.64 |
| | 2 | 50(51%) | .25 | .88 | -2.06 |
| | 3 | 22(22%) | 1.81 | 1.21 | 2.43 |
| | 4 | **3(3%)*** | 3.82 | .88 | 5.27 |
| 18. Ease of communication with PWA | 0 | 10(10%) | -5.32 | .65 | - |
| | 1 | 35(36%) | -1.42 | .98 | -5.41 |
| | 2 | 40(41%) | 1.03 | .80 | -.83 |
| | 3 | 10(10%) | 2.17 | 1.12 | 2.51 |
| | 4 | **3(3%)*** | 4.60 | .34 | 3.72 |
| 19. New way to communicate with PWA | 0 | 10(10%) | -4.72 | 1.48 | - |
| | 1 | 25(26%) | -1.90 | 1.47 | -5.28 |

| | | | | | |
|---|---|---|---|---|---|
| | 2 | 57(58%) | .80 | .95 | -1.75 |
| | 3 | **3(3%)*** | 3.38 | .13 | 4.23 |
| | 4 | **3(3%)*** | 4.47 | .31 | **2.80§** |
| 22. Help PWA communicate | 0 | **7(7%)*** | -5.51 | .81 | - |
| | 1 | 12(12%) | -3.36 | 1.21 | -4.39 |
| | 2 | 47(48%) | -.17 | .96 | -2.34 |
| | 3 | 24(24%) | 1.67 | 1.63 | 2.37 |
| | 4 | **8(8%)*** | 2.58 | 1.22 | 4.35 |
| **Outside influences & interactions** | | | | | |
| 8. Frustrated, angry, annoyed | 0 | **2(2%)*** | -3.52 | .84 | - |
| | 1 | 18(18%) | -.07 | .84 | -5.40 |
| | 2 | 33(33%) | 2.43 | .93 | -.62 |
| | 3 | 40(40%) | 3.36 | .88 | 1.18 |
| | 4 | **7(7%)*** | 4.90 | .94 | 4.84 |
| 26. Friendships | 0 | **3(3%)*** | -3.17 | .74 | - |
| | 1 | **3(3%)*** | -1.99 | .83 | -2.76 |
| | 2 | 21(21%) | 1.22 | .97 | -2.48 |
| | 3 | 55(54%) | 2.71 | .98 | .88 |
| | 4 | 19(19%) | 4.29 | .82 | 4.35 |
| 32. Education/learning | 0 | **1(1%)*** | -3.77 | .87 | - |
| | 1 | **1(1%)*** | **-4.60†** | .18 | -2.00 |
| | 2 | **4(4%)*** | -.98 | 1.31 | **-2.13§** |
| | 3 | 49(49%) | 2.07 | 1.35 | -.47 |
| | 4 | 46(46%) | 3.22 | 1.24 | 4.60 |

Indications of a rating scale problem: *<10 cases per category; †reversed average measures; ‡ category misfit; §disordered step calibrations.

b) *Unidimensionality*. Rasch-based PCA of the 26 items together confirmed the multidimensionality of the scale with 48% of the variance explained and an eigenvalue of 4.2 in the first contrast. These results suggest that it is not appropriate to calculate a summary score. Instead, unidimensionality of each subscale was investigated separately. Extremely misfit persons in each subscale were identified and removed due to their threat to unidimensionality. The person fit statistics for extremely misfit persons is displayed in table 6.7. Chi-square analysis revealed that, compared to well-fit persons, extremely misfit persons were more likely to be over 65 years old, live with the person with aphasia, and/or be married to the person with aphasia ($p<.05$).

Item fit analysis revealed three misfit items: #15 (care for other relatives) and #30 (paid or volunteer work) in the first subscale; and, #11 (focus, memory, decision-making) in the fifth subscale. The removal of items #15 and #11 was supported clinically as they did not conceptually fit with the other items in their respective subscales. However, item #30 was retained as it was theoretically appropriate in consideration of the content of the other items in the subscale and its retention also contributed to improved unidimensionality (i.e., eigenvalue <2.0 in the first contrast). The initial and final item fit statistics are displayed in tables 6.8 and 6.9.

The final Rasch derived principal component for factors 1 through 5, respectively, accounted for 72.6%, 71.4%, 69.9%, 67.7%, and 67.2% of the variance with no eigenvalues in the second component greater than 2.0, providing evidence for the unidimensionality of each subscale.

Table 6.7.

*Extremely misfit persons*.

| FM ID | Infit MnSq | Infit Zstd | Outfit MnSq | Outfit Zstd |
|---|---|---|---|---|
| **Health & daily life** | | | | |
| 038B | 5.16 | 3.47 | 5.49 | 3.18 |
| 049B | 2.44 | 2.50 | 2.26 | 2.31 |
| 050A | 2.50 | 2.62 | 2.57 | 2.31 |
| 051A | 2.18 | 2.07 | 2.46 | 2.44 |
| 066A | 2.37 | 2.58 | 2.46 | 2.67 |
| 074A | 3.36 | 3.02 | 3.82 | 3.32 |
| 185B | 2.80 | 2.85 | 2.71 | 2.77 |
| **Attitude & personal life** | | | | |
| 025A | 4.41 | 2.67 | 4.34 | 2.63 |
| 028A | 4.80 | 2.81 | 4.86 | 2.83 |
| 031A | 3.52 | 2.33 | 3.63 | 2.39 |
| 039A | 4.36 | 2.65 | 4.60 | 2.75 |
| 041A | 3.71 | 2.43 | 3.75 | 2.46 |
| 044A | 4.64 | 2.85 | 4.43 | 2.75 |
| 059B | 4.41 | 2.67 | 4.34 | 2.63 |
| 075A | 2.99 | 2.14 | 3.05 | 2.17 |
| **Helping others** | | | | |
| 029A | 4.06 | 2.51 | 5.21 | 2.04 |
| 050A | 7.04 | 3.15 | 8.07 | 3.14 |
| 066A | 4.67 | 2.70 | 9.90 | 3.16 |
| **Communication & emotions** | | | | |
| 029C | 3.97 | 3.12 | 4.07 | 3.15 |

| | | | | |
|---|---|---|---|---|
| 046A | 3.80 | 3.26 | 4.60 | 3.42 |
| 076A | 6.79 | 4.44 | 6.75 | 4.34 |
| 079A | 3.59 | 2.59 | 3.94 | 2.68 |
| 185B | 3.59 | 2.50 | 3.86 | 2.65 |
| 205 | 2.50 | 2.14 | 3.18 | 2.48 |
| **Outside influences & interactions** | | | | |
| 024A | 3.95 | 2.50 | 3.65 | 2.21 |
| 069A | 7.67 | 4.10 | 8.30 | 4.41 |
| 077A | 3.20 | 2.28 | 2.94 | 2.00 |

Table 6.8.

*Initial item fit statistics*.

| Item | Measure | SE | Infit MnSq | Infit Zstd | Outfit MnSq | Outfit Zstd |
|---|---|---|---|---|---|---|
| **Health & daily life** | | | | | | |
| 2. Health | -2.03 | .20 | .95 | -.2 | .69 | -1.1 |
| 3. Physical functioning | -.22 | .19 | .77 | -1.6 | .68 | -2.0 |
| 5. Stressed | .65 | 16 | .87 | -.9 | .88 | -.9 |
| 9. Emotional | .61 | .16 | 1.14 | 1.0 | 1.18 | 1.2 |
| 15. Care for other relatives | -.08 | .16 | 1.19 | 1.2 | 1.17 | 1.0 |
| 27. Recreational activities | .23 | .16 | .98 | -.1 | .97 | -.1 |
| 28. Social activities | .16 | .17 | .87 | -.8 | .81 | -1.1 |
| 29. Finances | .73 | .17 | .82 | -1.0 | .65 | -1.5 |
| 30. Paid or volunteer work | -.15 | .18 | 1.28 | .15 | 1.28 | 1.3 |
| **Attitude & personal life** | | | | | | |
| 10. Appreciative | -.76 | .15 | 1.12 | .8 | 1.14 | .9 |
| 33. Attitude | .56 | .16 | .89 | -.8 | .88 | -.8 |

| | | | | | | |
|---|---|---|---|---|---|---|
| 34. Personal changes | .21 | .16 | .91 | -.6 | .93 | -.4 |
| **Helping others** | | | | | | |
| 20. Source of social contact | .09 | .15 | 1.11 | .8 | 1.12 | .8 |
| 23. Speech therapy | -.70 | .17 | .67 | -2.2 | .69 | -1.8 |
| 24. Explain aphasia | -.33 | .15 | .89 | -.7 | .92 | -.4 |
| 31. Volunteer with PWA | .94 | .28 | 1.54 | 1.5 | .86 | -.2 |
| **Communication & emotions** | | | | | | |
| 1. Overall | .21 | .13 | .89 | -.7 | .85 | -1.0 |
| 4. Sad | .89 | .16 | .93 | -.4 | .96 | -.1 |
| 6. Worried | -1.16 | .17 | 1.05 | .4 | 1.03 | .3 |
| 18. Ease of communication with PWA | .48 | .15 | .95 | -.3 | .86 | -.9 |
| 19. New way to communicate with PWA | .19 | .16 | .96 | -.1 | 1.01 | .1 |
| 22. Help PWA communicate | -.61 | .15 | 1.14 | 1.0 | 1.17 | 1.1 |
| **Outside influences & interactions** | | | | | | |
| 8. Frustrated, angry, annoyed | .24 | .13 | .68 | -2.5 | .68 | -2.6 |
| **11. Focus, memory, decision-making** | **-.09** | **.14** | **1.52** | **2.8** | **1.34** | **1.8** |
| 26. Friendships | .32 | .13 | .94 | -.3 | .90 | -.5 |

| | | | | | | |
|---|---|---|---|---|---|---|
| 32. Education/learning | -.46 | .13 | .83 | -1.2 | .90 | -.6 |

Misfit items are bolded. SE=standard error; MnSq=mean square; Zstd=standardized Z value.

Table 6.9.

*Final item fit statistics*.

| Item | Measure | SE | Infit MnSq | Infit Zstd | Outfit MnSq | Outfit Zstd |
|---|---|---|---|---|---|---|
| **Health & daily life** | | | | | | |
| 2. Health | -2.01 | .24 | .94 | -.3 | .72 | -.6 |
| 3. Physical functioning | .23 | .22 | .75 | -1.6 | .59 | -2.3 |
| 5. Stressed | 1.21 | .19 | .89 | -.8 | .92 | -.5 |
| 9. Emotional | -.09 | .20 | 1.20 | 1.3 | 1.16 | 1.0 |
| 27. Recreational activities | .93 | .19 | 1.00 | .0 | .94 | -.3 |
| 28. Social activities | .75 | .20 | .88 | -.7 | .80 | -1.0 |
| 29. Finances | -1.08 | .21 | .69 | -1.7 | .54 | -1.1 |
| **30. Paid or volunteer work** | **.05** | **.23** | **1.43** | **2.0** | **1.45** | **1.6** |
| **Attitude & personal life** | | | | | | |
| 10. Appreciative | -.61 | .21 | 1.19 | 1.2 | 1.22 | 1.3 |
| 33. Attitude | .20 | .21 | .88 | -.8 | .82 | -1.2 |
| 34. Personal changes | .41 | .21 | .83 | -1.1 | .83 | -1.1 |

| | | | | | | |
|---|---|---|---|---|---|---|
| **Helping others** | | | | | | |
| 20. Source of social contact | .46 | .18 | 1.17 | 1.1 | 1.15 | .9 |
| 23. Speech therapy | -.88 | .21 | .66 | -2.1 | .66 | -2.1 |
| 24. Explain aphasia | -.42 | .20 | .76 | -1.5 | .69 | -1.1 |
| 31. Volunteer with PWA | .84 | .41 | 1.24 | 1.0 | .80 | -.1 |
| **Communication & emotions** | | | | | | |
| 1. Overall | -.48 | .16 | .83 | -1.2 | .81 | -1.1 |
| 4. Sad | -64 | .19 | .89 | -.7 | .85 | -.7 |
| 6. Worried | -.47 | .20 | 1.06 | .4 | 1.02 | .2 |
| 18. Ease of communication with PWA | .63 | .19 | .93 | -.5 | .86 | -.9 |
| 19. New way to communicate with PWA | .57 | .21 | .97 | -.1 | 1.05 | .3 |
| 22. Help PWA communicate | -.89 | .18 | 1.16 | 1.1 | 1.22 | 1.3 |
| **Outside influences & interactions** | | | | | | |
| 8. Frustrated, angry, annoyed | 1.48 | .17 | .87 | -.9 | .89 | -.7 |
| 26. Friendships | .26 | .19 | .92 | -.5 | .90 | -.6 |
| 32. Education/learning | -1.74 | .21 | 1.14 | 1.0 | 1.29 | 1.7 |

Misfit items are bolded. SE=standard error; MnSq=mean square; Zstd=standardized Z value.

c) *Local independence*. Examination of the residual item correlation matrix revealed that no items demonstrated correlations >.7. In addition to evidence of unidimensionality, this result suggests that the assumption of local independence has been met.

d) *Test targeting*. Figure 6.4 shows the item category threshold levels and person ability levels along the same logit axis for each of the 5 factors. Figure 6.5 presents the mean item difficulty levels and person ability levels calibrated in logits. For all factors, the item-difficulty range covered the range of person ability with a low proportion of floor (0-5.2%) and ceiling (0-4%) effects, but potential gaps of >.5 logits were observed between category thresholds (shown in figure 6.4). Item redundancy was assessed based on the item-person maps displayed in both figures 6.4 and 6.5. Along the logit scale, some redundancy was noted for mean item difficulty (e.g., items #9 and #30 in factor 1; and, items #1 and #6, #4 and #18 in factor 4). Though these items exhibited the same mean item difficulty levels, the category thresholds differed; thus, they can provide distinct information regarding person ability. For factors 2 and 4, the mean person ability and item difficulty were well matched. For factors 1, 3, and 5, the mean person ability was positively deviated from the mean item difficulty, indicating that this sample has a higher level of third-party functioning than the average difficulty level of the test items.

| Health & daily life subscale | Attitude & personal life subscale | Helping others subscale | Communication & emotions subscale | Outside influences & interactions subscale |
|---|---|---|---|---|

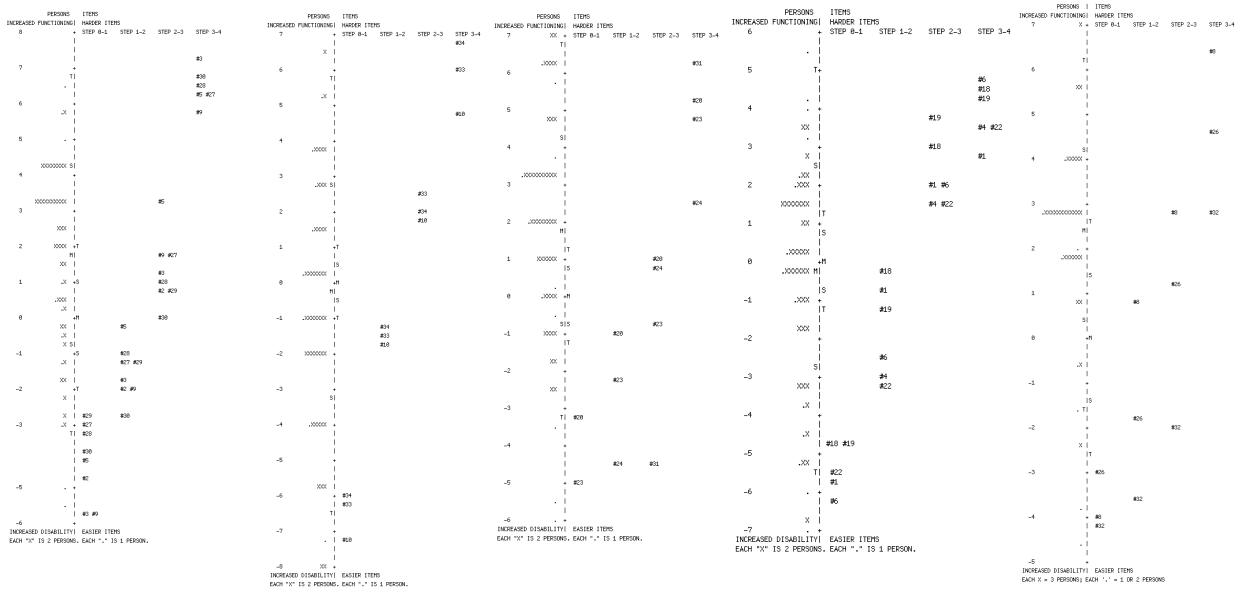


Figure 6.4. Item-person maps demonstrating step calibrations (0-1, 1-2, 2-3, 3-4) for the 5 rescored subscales of the SOS-Aphasia and the ability measures of participants. Higher values indicate greater item difficulty and people with greater third-party functioning; lower values indicate lower item difficulty and people with greater third-party disability. M denotes mean value, S denotes one standard deviation from the mean, T denotes two standard deviations from the mean.

| Health & daily life subscale | Attitude & personal life subscale | Helping others subscale | Communication & emotions subscale | Outside influences & interactions subscale |
|---|---|---|---|---|

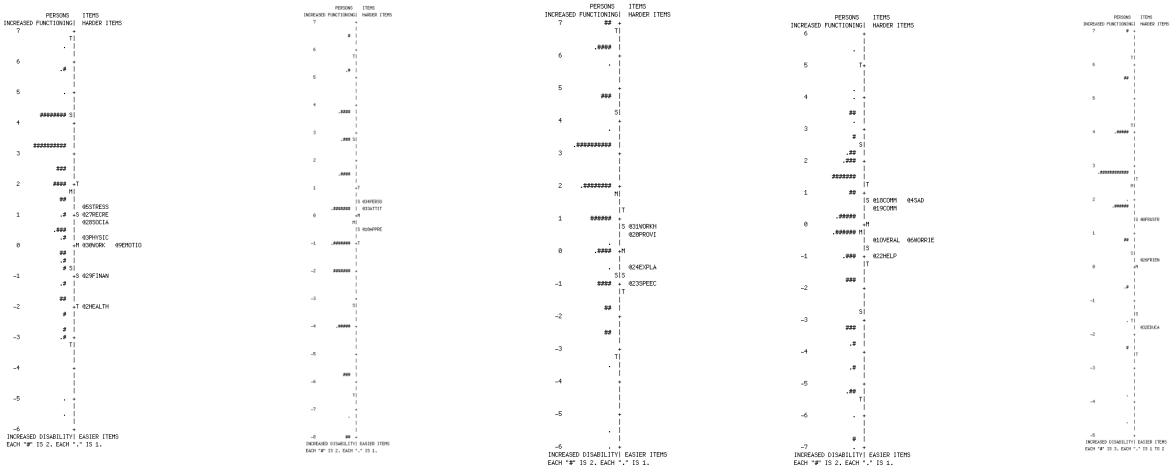

Figure 6.5. Item-person maps demonstrating the mean item difficulty for the 5 rescored subscales of the SOS-Aphasia and the ability measures of participants. Higher values indicate greater item difficulty and people with greater third-party functioning; lower values indicate lower item difficulty and people with greater third-party disability. M denotes mean value, S denotes one standard deviation from the mean, T denotes two standard deviations from the mean.

e) *Reliability*. The person separation reliability coefficient values of the final scale were .88, .80, .78, .89, and .59 for subscales 1 to 5, respectively. These results indicate acceptable reliability for factors 1 to 4.

f) *DIF*. DIF analysis was conducted to determine if item difficulty levels were varied based on family member age (divided by two groups: <65 years versus ≥65 years). No DIF items related to family member age were found. Gender DIF is also an important point of investigation; however, only 25 male participants included in this study do not form a large enough group for comparison. Table 6.10 presents the age DIF statistics.

Table 6.10.

*DIF statistics for age*.

| | Age <65 years Measure (SE) | Age ≥65 years Measure (SE) | Difference | Calculated *t* value | *p* value* |
|---|---|---|---|---|---|
| **Health & daily life** | | | | | |
| 2. Health | -2.26(.30) | -1.48(.39) | -.78 | -1.58 | .1185 |
| 3. Physical functioning | .31(.27) | .15(.40) | .16 | .33 | .7389 |
| 5. Stressed | 1.29(.23) | 1.09(.33) | .20 | .49 | .6227 |
| 9. Emotional | -.27(.25) | .47(.35) | -.73 | -1.69 | .0947 |
| 27. Recreational activities | 1.10(.23) | .57(.34) | .53 | 1.30 | .1992 |
| 28. Social activities | .85(.24) | .48(.36) | .38 | .87 | .3893 |
| 29. Finances | -.88(.26) | -1.57(.40) | .69 | 1.46 | .1490 |
| 30. Paid or volunteer work | -.34(.29) | .48(.40) | -.82 | -1.67 | .1000 |
| **Attitude & personal life** | | | | | |
| 10. Appreciative | -.76(.25) | -.40(.38) | -.36 | -.79 | .4348 |
| 33. Attitude | .16(.25) | .35(.39) | -.19 | -.41 | .6825 |
| 34. Personal changes | .59(.25) | .03(.39) | .56 | 1.21 | .2294 |
| **Helping others** | | | | | |
| 20. Source of social contact | .58(.22) | .18(.33) | .40 | 1.00 | .3214 |
| 23. Speech therapy | -.77(.26) | -1.12(.39) | .35 | .75 | .4558 |
| 24. Explain aphasia | -.54(.24) | -.15(.36) | -.39 | -.90 | .3714 |
| 31. Volunteer with PWA | .26(.50) | 1.61(.62) | -1.34 | -1.70 | .0934 |
| **Communication & emotions** | | | | | |
| 1. Overall | -.65(.21) | -.29(.28) | -.36 | -1.04 | .3034 |
| 4. Sad | .51(.24) | 1.01(.33) | -.50 | -1.22 | .2270 |
| 6. Worried | -.26(.25) | -.90(.34) | .63 | 1.48 | .1436 |

| | | | | | |
|---|---|---|---|---|---|
| 18. Ease of communication with PWA | .73(.23) | .41(.32) | .32 | .80 | .4256 |
| 19. New way to communicate with PWA | .68(.26) | .31(.34) | .36 | .84 | .4015 |
| 22. Help PWA communicate | -.92(.23) | -.71(.32) | -.20 | -.52 | .6040 |
| **Outside influences & interactions** | | | | | |
| 8. Frustrated, angry, annoyed | 1.64(.21) | 1.14(.31) | .51 | 1.35 | .1812 |
| 26. Friendships | .26(.23) | .23(.32) | .03 | .08 | .9336 |
| 32. Education/learning | -2.00(.26) | -1.25(.35) | -.75 | -1.72 | .0903 |

### 6.4.4 Feasibility

Twenty participants completed the SOS-Aphasia online in a mean time of 8 minutes and 43 seconds (SD=3:30, range=5:30-16:02). For all 104 completed SOS-Aphasia scales, the average item completion rate was 99.4% (range=91-100%). Twelve family members left one item blank, 3 left 2 items blank, and 1 left 3 items blank. A total of 9 different items were not completed by at least one person. Through exploratory factor analysis and Rasch analysis three of these items were excluded from the revised 24-item version of the SOS-Aphasia, while 6 remained (i.e., #8 – frustrated, angry, annoyed; #10 – appreciative; #22 – help PWA communicate; #23 – help with speech therapy; #24 – explain aphasia; #31 – volunteer with PWA). Ninety-eight (94%) participants completed the questionnaire independently; the rest opted to discuss their experience with the investigator while responding to each question.

### 6.4.5 Test-retest reliability

In order to determine test-retest reliability, 32 (31%) participants completed the SOS-Aphasia a second time. The mean time between administrations was 51 days (SD=42.6; range=6-201 days). Table 6.11 displays the test-retest reliability for each item and subscale of the SOS-Aphasia. Twenty-one items (87.5%) demonstrated moderate or greater reliability according to the weighted kappa results, with only 3 items showing fair reliability (Landis & Koch, 1977). Interpretation of ICC showed that factor 2 had moderate test-retest reliability with the other four factors demonstrating acceptable test-retest reliability.

Table 6.11.

*Test-retest agreement of revised SOS-Aphasia items (n=104).*

| Item | Exact Agreement (%) | <1 grade difference in agreement (%) | wκ | ICC (95% CI) |
|---|---|---|---|---|
| **Health & daily life** | | | | .91(.82-.96) |
| 2. Health | 22(68.8) | 32(100) | .71 | |
| 3. Physical functioning | 23(71.9) | 31(96.9) | .79 | |
| 5. Stressed | 21(65.6) | 29(90.6) | .64 | |
| 9. Emotional | 23(71.9) | 31(96.9) | .88 | |
| 27. Recreational activities | 26(81.3) | 30(93.8) | .87 | |
| 28. Social activities | 26(81.3) | 30(93.8) | .87 | |
| 29. Finances | 20(62.5) | 31(96.9) | .74 | |
| 30. Paid or volunteer work | 25(78.1) | 28(87.5) | .49 | |
| **Attitude & personal life** | | | | .59(.29-.78) |
| 10. Appreciative | 16(50.0) | 27(84.3) | .28 | |
| 33. Attitude | 14(43.8) | 26(81.3) | .51 | |
| 34. Personal changes | 14(43.8) | 26(81.3) | .58 | |
| **Helping others** | | | | .70(.47-.85) |
| 20. Source of social contact | 22(68.8) | 31(96.9) | .79 | |
| 23. Speech therapy | 24(75.0) | 30(93.8) | .89 | |
| 24. Explain aphasia | 14(43.8) | 22(68.8) | .45 | |
| 31. Volunteer with PWA | 24(75.0) | 28(87.5) | .28 | |
| **Communication & emotions** | | | | .87(.75-.93) |
| 1. Overall | 18(56.3) | 29(90.6) | .52 | |
| 4. Sad | 20(62.5) | 29(90.6) | .46 | |
| 6. Worried | 21(65.6) | 30(93.8) | .64 | |

| | | | | |
|---|---|---|---|---|
| 18. Ease of communication with PWA | 20(62.5) | 30(93.8) | .66 | |
| 19. New way to communicate with PWA | 18(56.3) | 31(96.9) | .69 | |
| 22. Help PWA communicate | 24(75.0) | 29(90.6) | .62 | |
| **Outside influences & interactions** | | | | .70(.46-.84) |
| 8. Frustrated, angry, annoyed | 18(56.3) | 28(87.5) | .48 | |
| 26. Friendships | 20(62.5) | 30(93.8) | .81 | |
| 32. Education/learning | 14(43.8) | 29(90.6) | .24 | |

## 6.5 DISCUSSION

This study described the development and validation of the SOS-Aphasia, a scale for measuring third-party functioning and third-party disability in family members of people with aphasia due to stroke. It represents an important contribution to rehabilitation measurement science by providing an example of how qualitative and quantitative methods, particularly IRT, can be combined to develop a scale within the ICF framework. These preliminary results provide evidence for the internal construct validity, feasibility, and test-retest reliability of the 24-item SOS-Aphasia with five subscales and two formats of a 5-point rating scale. The revised 24-item SOS-Aphasia is presented in Appendix A.

Through factor analysis, the multi-dimensionality of the SOS-Aphasia was established, confirming previous qualitative research findings of the multi-faceted nature of third-party functioning and third-party disability (Grawburg, et al., 2013b). Five subscales were identified, which underscore the pervasive effect of aphasia on the lives of family members in areas of Health and Daily Life, Attitude and Personal Life, Helping Others, Communication and Emotions, and Outside Influences and Interactions. Based on the Rasch rating scale analysis, two different 5-point rating scales were implemented. Factors 1, 3, 4, and 5 were optimized when the positive response options (i.e., mild positive change, moderate positive change, and complete positive change) were collapsed, while factor 2 was optimized when the negative response options were collapsed (i.e., mild problem, moderate-severe problem, complete problem). These findings may reflect the positive orientation of the items in the second factor (i.e., appreciative, personal changes, and attitude) where family members were likely to differentiate meaningfully between one of the three response options related to positive change. This is in contrast to the other four factors, which contained items that family members may have perceived as having changed more negatively (e.g., health, stressed, frustrated, angry, annoyed, etc.) and, thus, they selected meaningfully between grades of the problem experienced due to aphasia.

The SOS-Aphasia may be advantageous for assessment of family members of people with aphasia compared to existing measures of family members post-stroke. For example, in contrast to the Carer COAST (Long, Hesketh, & Bowen, 2009) and the Bakas Caregiver Outcome Measure (Bakas, et al., 2006), the SOS-Aphasia allows for specific assessment of family members' third-party functioning and third-party

disability secondary to aphasia, and indication of positive, neutral, and negative changes. Moreover, Rasch analysis of the SOS-Aphasia facilitates the conversion of ordinal-level to interval-level measurement and represents both item difficulty and respondent's ability along the same logit scale. Interval-level measurement is required for calculating a total overall score and subscale scores, and comparing changes in scores over time (Tennant, et al., 2004). Other advantages resulting from Rasch analysis of the SOS-Aphasia are that response scores do not need to be compared to a normative sample to be interpreted (i.e., the SOS-Aphasia is sample-free), and subsets of items can also be validly scored (e.g., if some items are left blank or if fewer items are given to reduce respondent burden) (Baylor, et al., 2011).

The SOS-Aphasia has applications for policy and practice in the implementation of family-centred care. In policy, the SOS-Aphasia may provide a source of objective evidence for including family members of people with aphasia in clinical practice. It may also provide an indication of the "stability and viability" of the support that family members provide to people with aphasia in acute care, rehabilitation, and community re-integration post-stroke (Tate, 2009). This is particularly relevant in countries, such as New Zealand and Australia, where there is an emphasis on community-based health care with increasing reliance on unpaid support often provided by family members (Ministry of Social Development;, 2008; Vecchio, 2008).

The conceptualisation of the SOS-Aphasia in the context of the ICF framework may ensure a common platform for enhancing communication regarding family-centred care between health professionals, policy-makers, and family members. Scales like the SOS-Aphasia may also provide data for the development of an ICF core set for third-party functioning and third-party disability. ICF core sets are designed to describe specific conditions by linking changes in functioning to the relevant ICF categories and may be used in multi-disciplinary outcome assessment (Geyh, et al., 2004). Whether via an ICF core set, or a scale such as the SOS-Aphasia, the measurement of third-party functioning and third-party disability in aphasia may provide guidance for developing aphasia and stroke care pathways that incorporate family-centred care.

The ICF vocabulary and structure that provided the foundation for the SOS-Aphasia may also act to clarify family members' needs in the clinical practice. Applications of the SOS-Aphasia include assessment of family member outcomes for goal-setting and measurement of intervention efficacy. Even if the SOS-Aphasia is not scored, its use in clinical practice may enable conversations between family members and health professionals providing a vehicle for the early identification of family members in need of rehabilitation or referral. Clinicians should be aware that the responses of some family members cannot be interpreted accurately as they do not fit the expectations of the Rasch model and are identified as "extremely misfit persons". The characteristics of extremely misfit persons identified in this study (i.e., over 65 years old, live with the person with aphasia, and/or be married to the person with aphasia) accords with real situations where the family members with those characteristics may rate the impact of having a person with aphasia on their lives unexpectedly negatively or positively due to their direct physical, emotional, or financial associations. Future research will establish the effectiveness of the SOS-Aphasia in identifying at-risk family members for participation in intervention programs that aim to prevent or minimise third-party disability, as well as the utility of the SOS-Aphasia in the development of rehabilitation goals for family members.

### 6.5.1 Limitations and future research directions

Validation of the SOS-Aphasia is a cumulative, ongoing process that will benefit from the development of additional SOS-Aphasia items and testing with a larger, more diverse sample. The presence of item gaps suggests that additional test items need to be generated in order to provide response options along the logit continuum. This will allow more precise differentiation of family members' levels of third-party functioning and third-party disability, and accurate assessment of changes over time (Bond & Fox, 2012). As well as the exploration of the need for additional SOS-Aphasia items, the rewording of any inappropriate or awkward items can help to address item gaps, and also improve reliability, and response rate (Linacre, 2013). Conducting cognitive interviews with family members (Desimone & Le Floch, 2004) and consultation with experts (Velozo, et al., 2012) may help to inform this process.

Though the inclusion of 104 participants is generally adequate for this type of analysis (Linacre, 2002), the sample size may be considered small due to the heterogeneity of the sample, the low participant to item ratio, and increased variability that may be attributed to the length of the 7-point rating scale (Devellis, 2012). Testing of the SOS-Aphasia on a larger sample is warranted to address some of the study limitations. For example, despite being identified as misfit to the Rasch model expectations, item #30 was retained as it was considered to be conceptually similar to other items in the subscale and also contributed to the unidimensionality. A larger sample would provide further evidence to support or contradict this decision (Linacre, 2004). The inclusion of participants with more extreme ability may improve low person reliability, identified in factor 5, as well as test targeting (Linacre, 2013). A larger proportion of male family members is necessary to investigate the possibility of gender DIF, particularly as female family members may be more severely impacted by aphasia (Bakas et al., 2006; Kinsella & Duffy, 1978; Pringle et al., 2010). Given that the impact of aphasia changes with time (Grawburg, Howe, Worrall, & Scarinci, 2013b; Marshall, 2002), it would also be useful to include more participants with aphasia who are less than one year post onset. In future studies, the time interval between administration of the test and retest should be more consistent to establish clinically suitable temporal stability (i.e., ICC>.90) (Portney & Watkins, 2009).

## 6.6 CONCLUSION

The SOS-Aphasia is a self-report measure of third-party functioning and third-party disability based on the ICF that was developed through a unique and rigorous mixed methods protocol that included qualitative interviews and Rasch analysis. Though further research is needed to address the limitations of this study, the SOS-Aphasia demonstrated preliminary evidence of good psychometric properties. From a practice and policy perspective, measurement of third-party functioning and third-party disability may provide a more complete indication of the total cost of aphasia due to stroke and provide data for establishing family-centred care goals that will likely lead to improved outcomes for both family members and people with aphasia.

# CHAPTER 7

# SUMMARY, DISCUSSION, & CONCLUSION

## 7.1 SUMMARY

This research has contextualised the positive and negative effects of aphasia on family members within a framework of functioning, disability, and health, demonstrating that family members experience third-party functioning and third-party disability secondary to their significant other's aphasia. It also describes the development and validation of the SOS-Aphasia, a scale for measuring third-party functioning and third-party disability in family members of people with aphasia.

Two systematic reviews of the literature, contained in Chapters 2 and 3, were conducted to meet the first objective of the thesis, namely, to provide an up-to-date summary of the current literature with respect to third-party functioning and third-party disability. In the first review, the reported negative effects of aphasia on family members were mapped to one domain within the Body Functions component of the ICF and seven domains within the Activities and Participation component (Grawburg, et al., 2013a). In the second review, the positive effects of aphasia on family members were extracted from the literature with findings mapped to one domain within the Body Structures component and two domains within the Activities and Participation component (Grawburg, et al., 2012). These review studies also revealed gaps in our understanding of third-party functioning and third-party disability and the limited consensus between studies, providing an agenda for further research in this area. In particular, the results indicated the need for replication of existing findings and continued investigation of positive and negative family member outcomes with the inclusion of the perspective of younger family members (i.e., children and teenagers).

Based on the results of the systematic reviews, a qualitative-quantitative sequential mixed methods study was conducted within the post-positivist paradigm to further describe third-party functioning and third-party disability in aphasia, and to

develop the SOS-Aphasia, a tool for measuring third-party functioning and third-party disability in family members of people with aphasia. The results of the qualitative phase were presented in Chapters 4 and 5. To meet the second objective of the thesis, 20 family members (including 4 less than 18 years old), participated in individual in-depth semi-structured interviews. The interviews underwent qualitative content analysis, revealing new information about the lived experience of family members of people with aphasia, particularly positive and negative changes associated with third-party functioning and third-party disability (Grawburg, et al., 2013b). Family members' reports of the positive effects of aphasia (i.e., third-party functioning) were grouped into five categories: (1) emotions; (2) communication; (3) relationships; (4) recreational activities and social life; and, (5) paid/volunteer work or education. Examples of positive changes corresponding to these categories included increased appreciation, talking with the person with aphasia more openly, becoming closer to extended family, taking up new hobbies, and learning about aphasia and stroke. Negative family member outcomes (i.e., third-party disability) were also reported in these five categories, with additional negative effects related to: (6) domestic and caregiving responsibilities; and (7) finances. Family members reported negative changes (corresponding to these categories) such as guilt, difficulty communicating with the person with aphasia, feeling less close to the person with aphasia, giving up hobbies, working fewer hours, doing administrative tasks for the person with aphasia, and increased spending related to assisting the person with aphasia.

Research codes were subsequently mapped to ICF codes to provide a description of third-party functioning and third-party disability and an example of the application of the ICF framework to family members, meeting the third objective of the thesis (Grawburg, Howe, Worrall, & Scarinci, 2013c). Of the 124 research codes identified, 32 codes were mapped to 2 domains within the Body Functions component, 85 codes were mapped to 8 domains within the Activities and Participation component, 6 were identified as health conditions, and 1 was associated with general quality of life. These results highlighted the pervasive effect of aphasia on family members' health and daily lives.

In Chapter 6, the development and validation of the SOS-Aphasia were presented, meeting the final objective of this thesis. The content of the SOS-Aphasia items was based on the qualitative study results with the ICF influencing the structure

of the response scale. Factor analysis revealed 5 subscales of the SOS-Aphasia: (1) Health and daily life, (2) Attitude and personal life, (3) Helping others, (4) Communication and emotions, and (5) Outside influences and interactions. Based the results of factor analysis and Rasch analysis, 10 items were deleted from the original SOS-Aphasia. The final 24-item SOS-Aphasia demonstrated evidence of acceptable internal construct validity, reliability, and feasibility. Further research is required to address limitations through the generation of additional items and testing with a larger, more diverse sample.

## 7.2 IMPLICATIONS FOR PRACTICE AND POLICY

The application of the ICF and third-party functioning and third-party disability to family members has extensive implications for rehabilitation and policy (also discussed in Chapter 5 and throughout the thesis). Though preliminary, the results of this thesis provide a starting point for addressing existing barriers to the implementation of family-centred care in aphasia. In particular, these findings generally show how use of the ICF framework and the terms third-party functioning and third-party disability can provide a structure for depicting the impact of a health condition on family members. The development of policies based on this research may facilitate increased funding for family-centred practice in aphasia with time and resources apportioned for supporting family members. In addition, the SOS-Aphasia is a tool that can provide data for informing these policies and measuring their effectiveness.

### 7.2.1 Family-Centred Care Policy

The presence of third-party functioning and third-party disability in family members of people with aphasia, revealed in this thesis, provides justification for policy that supports family members to the same degree as the person with aphasia. Clinicians have indicated that they have difficulty including family members in rehabilitation, at least in part, due to time and resource constraints (Dalemans, de Witte, Wade, & van den Heuvel, 2010; Johansson, Carlsson, & Sonnander, 2011; Law, et al., 2010). The extensive effects of aphasia on family members, in combination with clinicians' reports of insufficient time and resources for assisting

them, means that policy supporting additional funding for family-centred care is required. Contextualising the effects of aphasia on family members within an accepted disability framework ensures consistency in reporting that may improve communication between clinicians, researchers, and policy-makers. Data generated through use of the SOS-Aphasia may provide evidence for policy amendments that lead to increased budgets for family-centred care. Further, the international and multidisciplinary recognition of the ICF strengthens the rationale behind policy that supports increased funding and resources for family members.

### 7.2.2 Third-Party Functioning and Disability in Family-Centred Rehabilitation

From a rehabilitation perspective, this thesis revealed the widespread effects of aphasia that potentially impact on most areas of family members' functioning, underscoring the importance of family-centred care. Indeed, one of the most significant implications of this research is the value of including family members in all stages of care to prevent or lessen the development of third-party disability. Support of family members is also crucial for the rehabilitation and recovery of people with aphasia (Carnworth & Johnson, 1987; Lapointe, 2011; Sorin-Peters, 2003), providing further justification for their inclusion in rehabilitation. Guidelines for the care of family members of people with stroke have been suggested in order to address their needs as patients, in addition to their role in supporting the person with stroke (Holland & Fridriksson, 2001; van Heugten, Visser-Meily, Post, & Lindeman, 2006; Visser-Meily, Post, et al., 2009). Due to the different ways that clinicians can view family members (i.e., as caregiver, client, and family member) (Visser-Meily, et al. 2006), clinicians need to examine their purpose in supporting family members to ensure appropriate goals and mutual understanding (Michallet, et al., 2001). Reinforced by the findings of this thesis, it has also been suggested that comprehensive aphasia rehabilitation should include interventions to help family members adjust to aphasia (Helm-Estabrooks & Albert, 2004; Holland & Fridriksson, 2001; Lapointe, 2011; Le Dorze & Brassard, 1995).

Though other health professionals can facilitate family-centred care, in the case of aphasia, speech-language pathologists may be in the best position to monitor the third-party functioning and third-party disability of family members due to their

focus on communication problems (Buck, 1968; Pring, 1999). However, despite their speciality in communication disorders, speech-language pathologists may not be inherently better at ensuring adequate communication with family members. For example, one study showed that, in acute care, speech-language pathologists met less than half the family members of people they saw with stroke, a lower proportion than occupational therapists, physical therapists, and social workers (Mackenzie, et al., 2007). This outcome may be related to policy and staffing, but it also underscores the need for an overt expansion of the scope of practice and training of speech-language pathologists to include skills such as adult education, family systems theory, and counselling (Sorin-Peters, 2004). Speech-language pathologists also need to be aware that while family members of people with aphasia are faced with communication changes, they must also cope with changes secondary to the stroke, in addition to other life changes (Grawburg, et al., 2013b; Michallet, et al., 2003).

### 7.2.3 Clinical Uses of the SOS-Aphasia

The SOS-Aphasia is an example of a scale that can be used to measure and report third-party functioning and third-party disability in family members of people with aphasia. It expands upon existing family member stroke measures, such as the Carer COAST (Long, Hesketh, & Bowen, 2009) and the Bakas Caregiver Outcome Scale (Bakas et al., 2006), to provide a more thorough assessment that includes items that target changes specifically related to communication (i.e., communicating on behalf of the person with aphasia) with positive, negative, and neutral response choices. Furthermore, Rasch analysis resulted in the generation of SOS-Aphasia items with a logit interval scale providing an indication of third-party functioning and third-party disability based on the item difficulty rather than in comparison to a normative sample or researcher-defined categories (Baylor, et al., 2011).

The SOS-Aphasia can be used in family member assessment, goal-setting, and intervention planning. It provides a brief, simple method for evaluating the needs of family members during all phases of care. Clinicians can use the SOS-Aphasia to identify areas of difficulty for family members in order to provide appropriate assistance through support, rehabilitation, or referral. The SOS-Aphasia can also be used to highlight areas of positive change or improved functioning that can form the basis of goals that build upon these strengths. For example, family member participants in this study reported positive changes associated with learning about

aphasia, as well as better relationships with other family members and friends. Access to information and increased knowledge of aphasia is associated with improved family member outcomes (Avent, et al., 2005; Le Dorze, et al., 2008; Williams, 1993). Similarly, family members' adaptation and functioning following the onset of aphasia may improve with social support (Bury, 1991; Carnwath & Johnson, 1987; Le Dorze, et al., 2008; Rice, et al., 1987; Visser-Meily, et al., 2009). Thus, these positive changes should be cultivated when setting strength-based goals. However, individual assessment is warranted as the circumstances related to improved functioning can vary. For example, while social support may be beneficial for some family members, it may not be sufficient to assist with all required support and respite needs (Le Dorze & Signori, 2009). Moreover, third-party disability due to aphasia may result in decreased social participation, which is inherent to social support (Lyons, Mickelson, Sullivan, & Coyne, 1998).

Use of the SOS-Aphasia may broaden the scope of speech-language pathology intervention beyond communication skills training to include other areas of the family members' functioning that have been impacted by aphasia. Though communication skills training programs may improve family members' ability to communicate with the person with aphasia (Simmons-Mackie, Raymer, Armstrong, Holland, & Cherney, 2010), they are inadequate for addressing the multi-faceted needs of family members demonstrated in this thesis. Family members' emotions related to aphasia (e.g., anger, grief, acceptance, etc.) may surface even in communication-based training programs that do not include counselling or other supports for coping with difficult emotions (Sorin-Peters, 2004). Besides communication skills training, the few previous family member intervention studies conducted in aphasia have explored aphasia education and psychological support with limited success (Servaes et al., 1999). The stroke literature provides examples of more holistic interventions that show potential for assisting family members of people with aphasia, such as discharge training aimed at family members (Shyu, Chen, Chen, Wang, & Shao, 2008) and counselling-style intervention with a focus on active problem-solving behaviour and support seeking behaviour (van Heugten, et al., 2006). Cameron and Gignac (2008) have developed a framework for supporting family members of people with stroke from acute care to the community emphasizing the importance of family-centred care in transitions throughout the continuum of care. Further research investigating intervention for

family members of people with aphasia will inform how family-centred care should be integrated into existing stroke and aphasia pathways.

### 7.2.4 Implications for the ICF & Previous Research

The finding that aphasia can lead to third-party functioning and third-party disability supports the model proposed by Scarinci, et al. (2009) conceptualising how a significant other's health condition can act as an environmental factor that influences family member's functioning, disability, and health. In contrast to the gradual onset of a hearing impairment, "*The sudden and usually unexpected nature of a stroke* [and aphasia] *together with the wide range of physical, social, behavioural, emotional, and financial outcomes encountered during rehabilitation present particular challenges and difficulties for carers*" (Mackenzie, et al., 2007, p. 111). Compared to the third-party disability in hearing impairment, family members of people with aphasia experience a broader scope of difficulties. Family members of people with aphasia and hearing impairment experienced communication changes, the responsibility of assisting the person with the communication disorder, and relationship changes associated (Scarinci, et al., 2009); however, aphasia was also associated with changes in focus, handling stress, chores, education, employment, finances, as well as development or worsening of a health condition. In the context of a disability framework, the changes to family members' Functioning and Disability identified in this thesis are similar to the family member handicaps identified by Le Dorze and Brassard (1995), showing that family members experienced changes in the areas of emotions, communication, relationships, work, and social involvement. This thesis expanded these findings to include changes to health, finances, and providing support to others affected by aphasia. Overall, this research suggests that third-party functioning and third-party disability be incorporated in future versions of the ICF to better capture the full impact of a health condition, including the effects on family members.

Limitations of the ICF coding system have been identified in this thesis. They include: i) the lack of provision for coding the magnitude of positive functioning in the Body Functions and Structures and Activity and Participation components;, ii) the difficulty in accounting for increases in functioning that have a negative effect on the family members; and, iii) the lack of clarity in coding between the Body Functions and Structures and Personal Factors components. These limitations are discussed

below and may be addressed through the modifications of the coding system in future editions of the ICF.

First, it is suggested that the ICF include a range of qualifier descriptors for rating the magnitude of positive functioning, in addition to the current scale for rating the magnitude of negative functioning. The ICF states, "at the user's discretion coding scales can be developed to capture the positive aspects of functioning" (WHO, 2001, p. 223). However, there is only one qualifier rating currently available to represent both a neutral rating and a range of positive magnitude ratings for the ICF components (i.e., 0=*No problem*; or, 0=*No impairment* for Body Functions and Structures codes, and 0=*No difficulty* for the Activity and Participation codes) (WHO, 2001). Inclusion of a range of positive ratings for these qualifiers would facilitate a more holistic depiction of an individual's functioning and disability, and the ability to consistently differentiate between positive and neutral ratings.

Second, it is recommended that future editions of the ICF include a method for coding the individual's interpretation of the specific functioning and disability codes. Some changes associated with increased performance that family members perceive as negative may be missed or misleadingly classified as not being a problem for the individual. For example, many family members described having to assist the person with aphasia as being a problem for them. Since the family member is able to assist, this could be considered an increase in performance, and might not be coded as a part of the disability. However, increased responsibilities often have a negative effect on family members and may contribute to third-party disability. Identification of negative changes, even if associated with improved performance, is important in the prevention of third-party disability as the family member and person with aphasia transition through the health care system and adapt to life with aphasia. Furthermore, though the ICF does not yet include qualifier descriptors to differentiate the magnitude of positive changes, it does allow for neutral and positive ratings (WHO, 2001). All of these ICF guidelines were considered when mapping the codes from the qualitative research study to the ICF in Chapter 5 of this thesis. It is recommended that future versions of the ICF explicitly address the issue of how to code increases in performance that result in disability.

Third, future editions of the ICF must provide clear guidance for appropriate designation of Body Function codes versus Personal Factors codes, most notably in

the Mental Functions domain of the Body Functions component (Grawburg, 2013c; Threats, 2007). For example, direction should be stated on whether a change in optimism is most suitably coded by b1265 Optimism or as a Personal Factor reflecting normal variation in optimism. Threats (2007) has suggested that Body Function codes should only be used in cases of pathology and not normal variation in feelings. However, in this thesis, changes that family members attributed to aphasia (e.g., worried, irritated, and appreciative) were consistently mapped to the Mental Functions domain of the Body Functions component. This was because Personal Factors are identified in the ICF as, "The particular background of an individual's life and living, and comprise features of the individual that are not part of a health condition or health states." (WHO, p. 17), and the family member would no longer experience the reported change should their significant other no longer have aphasia (Badley, 2008).

Another ICF related issue is that of accounting for the influence of pre-existing family member characteristics (i.e., Personal Factors) that affect the development of third-party functioning and third-party disability, such as individual life experience, personality, and temperament (Threats, 2012). Though Personal Factors are not coded by the current version of the ICF, other investigations have revealed significant associations between pre-existing family member characteristics and outcomes. In the field of hearing impairment, one study has shown that decreased relationship satisfaction, spousal age difference, and the spouse's perception of the hearing impaired partner's disability are predictive factors in the development of moderate or severe third-party hearing disability (Scarinci, et al., 2012). In the stroke literature, previous studies have shown that female family members (Bakas, et al. 2002; Choi-Kwon et al., 2005), daughter-in-laws of the person with stroke (Bakas et al. 2002; Choi-Kwon et al., 2005), the presence of aphasia (Bakas, et al. 2002; Choi-Kwon et al., 2005), the presence of other communication disorders (Bakas et al., 2002), and stress and coping (Bakas, et al., 2002) are associated with negative family member outcomes (e.g., poorer quality of life and caregiver burden). Further research will determine if pre-existing characteristics of the individuals in this sample are associated with the development of third-party functioning and third-party disability in aphasia. Variables to be investigated include the family member's gender, age, anxiety and depression, relationship satisfaction, and whether or not they are living

with the person with aphasia. The nature of the relationship between the family member and the person with aphasia, the difference in their ages, and variables related to the person with aphasia (e.g., gender, age, aphasia severity, stroke-related disability) will also be investigated. Though Personal Factors are not yet coded by the ICF, their inclusion and consideration in research and clinical practice is vital as they can impact upon the family member's ability to participate in and benefit from rehabilitation, in addition to impacting the development of third-party functioning and third-party disability (Threats chapter, 2012). Future editions of the ICF that include Personal Factor codes, will facilitate improved consistency in documentation of these important variables for better understanding functioning and disability.

## 7.3 LIMITATIONS AND FUTURE RESEARCH DIRECTIONS

There are a number of limitations of this research that affect interpretation of the findings and provide directions for future research. The limitations, also raised in each chapter, include the small sample size and limited variation in the sample, the cross-sectional nature of the studies, and the issue of attributing these findings to aphasia compared to the stroke as a whole.

Though the 104 participants in the quantitative study are considered to be adequate for the types of analyses conducted, the validity and reliability of the SOS-Aphasia may be improved when tested with a larger number of participants, and, in particular, a more diverse sample. Specifically, future studies should include a greater number of male family member participants, more family members under 18 years of age, family members of people with acute aphasia, and family members from minority culture groups. Personal Factors (e.g., gender, age, culture, pre-existing physical, mental, and social health, and personality) and Environmental Factors (e.g., quality and availability of health services, supportive relationships, and post-onset time) are likely to influence an individual's experience of third-party functioning and third-party disability, and may be associated with bias in responses (i.e., differential item functioning) on the SOS-Aphasia. Future studies may also investigate characteristics associated with the development of third-party functioning and third-party disability.

The evidence presented in the thesis is cross-sectional in nature. Results from the qualitative study suggest that the impact of aphasia changed over time, as family members recalled their experiences from the onset of their significant other's aphasia and the time while they were in acute care, to the time of the interview, when the person with aphasia was living in the community. However, future longitudinal studies would improve our understanding of the trajectory of third-party functioning and third-party disability, as well as the influence of Personal Factors (i.e., age, gender, personality, coping strategies) in the development of third-party functioning and third-party disability, and provide an indication of the responsiveness of the SOS-Aphasia in identifying changes over time. Timing of data collection in longitudinal research should be conducted with consideration for rehabilitation stages and family member transitions and not necessarily conducted in relation to pre-defined time intervals (Reinhard, Given, Petlick, & Bemis, 2008).

An additional limitation of these findings is the difficulty attributing the changes to family members' Functioning and Disability to aphasia, and not stroke or other life changes, despite attempts to control for other factors (i.e., family members were asked to specifically focus on the consequences of aphasia, rather than the stroke in general, and the SOS-Aphasia items begin with the statement, "Because of my family member's aphasia…"). This problem has reported in other studies of family members of people with aphasia due to stroke (Bakas, et al., 2006; Barrow, 2008; Le Dorze & Signori, 2010). Though some authors have indicated that the effects on family members are primarily due to aphasia, and not stroke (Kinsella & Duffy, 1979; Le Dorze & Brassard, 1995; Le Dorze & Signori, 2009), family member participants in this study described difficulty separating the influence of aphasia from the influence of stroke. Pinpointing the source of these changes is important from a theoretical perspective in order to accurately depict the sequelae of third-party functioning and third-party disability in aphasia. From a policy perspective, funding can be more fairly and adequately distributed if the contribution of aphasia to family members' third-party functioning and third-party disability is better understood. However, due to the simultaneous onset of stroke and aphasia, family members may be unable to discern the impact of aphasia from stroke. Therefore, future studies comparing third-party functioning and third-party disability in family members of people with aphasia with and without stroke may better isolate the impact of aphasia.

Though the difficulty in attribution may be seen as a limitation, it can also serve as a reminder that family members are an inextricable part of their environment, effected by aphasia, stroke, and other life events, all of which may influence rehabilitation planning.

## 7.4 CONCLUSION

This thesis shows that family members of people with aphasia due to stroke experience significant and widespread changes to their health and daily lives, emphasizing the need for services specifically for family members. The WHO has projected that by 2020, stroke and heart disease will be the world's leading cause of death and disability (WHO, 2004); however, due to the lack of infrastructure for family-centred care in stroke and aphasia, there is a probable shortfall of services for family members. This research produced the SOS-Aphasia, a valid and reliable method of measuring third-party functioning and third-party disability in family members of people with aphasia, which can be used to generate evidence in support of family-centred care and policy. Moreover, use of the common structure and vocabulary of the ICF to contextualise the nature and extent of third-party functioning and third-party disability facilitates improved communication between health professionals, researchers, and policy-makers. Thus, from a humanitarian perspective, this research provides a rationale for implementing changes to health and social policy with implications for family members, people with aphasia, and society at large.

# REFERENCES

Al-Janabi, H., Frew, E., Brouwer, W., Rappange, D., & Van Exel, J. (2010). The inclusion of positive aspects of caring in the Caregiver Strain Index: Tests of feasibility and validity. *International Journal of Nursing Studies, 47*, 984-993.

Antonucci, T., & Akiyama, H. (1987). Social networks in adult life and a preliminary examination of the convoy model. *Journal of Gerontology, 42*, 519-527.

Artes, R., & Hoops, R. (1976). Problems of aphasic and non-aphasic stroke patients as identified and evaluated by patients' wives. In Y. L. Hoops (Ed.), *Recovery in aphasics* (pp. 31-45). Amsterdam: Swets & Zeitlinger B. V. .

Avent, J., Glista, S., Wallace, S., Jackson, J., Nishioka, J., & Yip, W. (2005). Family Information Needs about Aphasia. *Aphasiology, 19*(3), 365-375.

Bacon, E., Milne, D. L., Sheikh, A. I., & Freeston, M. H. (2009). Positive experiences in caregivers: An exploratory case series . *Behavioural and Cognitive Psychotherapy, 37* (1), 95-114.

Badley, E.M. (2008). Enhancing the conceptual clarity of the activity and participation components of the International Classification of Functioning, Disability and Health. Social Science & Medicine, 66, 2335-2345.

Bakas, T., Kroenke, K., Plue, L. D., Perkins, S. M., & Williams, L. S. (2006). Outcomes among family caregivers of aphasic versus nonaphasic stroke survivors. *Rehabiliation Nursing, 31*, 33-42.

Barrow, R. (2008). Listening to the voice of living life with aphasia: Anne's story. . *International Journal of Language and Communication Disorders, 43*(S1), 30-46.

Bartlett, M. S. (1954). A note on the multiplying factors for various chi square approximations. *Journal of the Royal Statistical Society, 6(Series B)*, 296-298.

Baylor, C., Hula, W., Donovan, N., Doyle, P. J., Kendall, D., & Yorkston, K. (2011). An Introduction to Item Response Theory and Rasch Models for Speech-Language Pathologists. *American Journal of Speech-Language Pathology, 20*, 243-259.

Bevans, M. F. (2012). Caregiving Burden, Stress, and Health Effects Among Family Caregivers of Adult Cancer Patients. *Journal of the American Medical Association, 307*, 398-403.

Bond, T. G., & Fox, C. M. (2012). *Applying the Rasch Model : Fundamental Measurement in the Human Sciences* (2nd ed.). New York, NY: Routledge.

Bowen, D. J., Kreuter, M., Spring, B., Cofta-Woerpel, L., Linnan, L., Weiner, D., et al. (2009). How we design feasibility studies. *American Journal of Preventive Medicine, 36*, 452-457.

Bowling, J. (1977). Emotional problems of relatives of dysphasic patients. *Journal of Human Communication Disorder , 5*, 29-41.

Brown, K., Worrall, L., Davidson, B., & Howe, T. (2011). Living successfully with aphasia: family members share their views. *Topics in Stroke Rehabilitation, 18*, 536-548.

Buck, M. (1968). *Dysphasia: Professional guidance for family and patient*. Englewood Cliffs, NJ: Prentice Hall.

Burman, M. E. (2001). Family caregiver expectations and management of the stroke trajectory . *Rehabilitation Nursing, 26* (3), 94-99.

Bury, M. (1991). The sociology of chronic illness: a review of research and prospects. *Sociology of Health and Illness, 13* (4), 451-468.

Byrne, K., & Orange, J. B. (2005). Conceptualizing communication enhancement in dementia for family caregivers using the WHO-ICF framework. *International Journal of Speech-Language Pathology, 7*, 187-202.

Cameron, J. I., & Gignac, M. A. (2008). 'Timing It Right'': A conceptual framework for addressing the support needs of family caregivers to stroke survivors from the hospital to the home. *Patient Education and Counseling, 70* (3), 305-314.

Carlson, J. A. (2010). Avoiding traps in member checking. *The Qualitative Report, 15*, 1102-1113.

Carnworth, T. C., & Johnson, D. A. (1987). Psychiatric morbidity among spouses of patients with stroke. *British Medical Journal, 294*, 409-411.

Cattell, R. B. (1966). The scree test for the number of factors. *Multivariate Behavioral Research, 1*, 629-637.

Chien, C. W., & Bond, T. G. (2009). Measurement properties of fine motor scale of Peabody developmental motor scales-second edition: a Rasch analysis. *American Journal of Physical Medicine and Rehabilitation, 88* (5), 376-386.

Choi-Kwon, S., Hwa-Sung, K., Kwon, S. U., & Kim, J. S. (2005). Factors affecting the burden on caregivers of stroke survivors in South Korea. *Archives of Physical Medicine and Rehabilitation, 86*, 1043-1048.

Christensen, J., & Anderson, J. (1989). Spouse adjustment to stroke: aphasic versus nonaphasic partners. *Journal of Communication Disorders , 22*, 225-231.

Cieza, A., Geyh, S., Chatterji, S., Kostanjsek, N., Üstün, B., & Stucki, G. (2005). ICF linking rules: an update based on lessons learned. *Journal of Rehabilitation Medicine, 37*, 212-218.

Clemson, L., Fitzgerald, M. H., & Mullavey-O'Byrne, C. (1999). Family perspectives following stroke: The unheard stories. *Topics in Stroke Rehabilitation , 6* (1), 60-77.

Code, C. (2012). Apportioning time for aphasia rehabilitation. *Aphasiology, 26*, 729-735.

Costello, A. B., & Osborne, J. W. (2005). Best Practices in Exploratory Factor Analysis: Four Recommendations for Getting the Most From Your Analysis. *Practical Assessment, Research and Evaluation, 10* (7), 1-9.

Creswell, J. W. (2009). *Research design: qualitative, quantitative, and mixed methods approaches* (3rd ed.). Thousand Oaks, California: Sage Publications, Inc.

Critical Appraisal Skills Programme (CASP), NHS. (2003). *Critical Appraisal Skills Programme (CASP): appraisal tools*. (N. P. Unit, Ed.) Retrieved September 20, 2012 from http://www.casp-uk.net/wp-content/uploads/2011/11/CASP_Systematic_Review_Appraisal_Checklist_14oct10.pdf

Dalemans, R. J., de Witte, L., Wade, D., & van den Heuvel, W. (2010). Social participation thorugh the eyes of people with aphasia. *International Journal of Language and Communication Disorders, 45*, 537-550.

Denman, A. (1998). Determining the needs of spouses caring for aphasic partners. *Disability and Rehabilitation, 20* (11), 411–423.

Desimone, L. M., & Le Floch, K. C. (2004). Are We Asking the Right Questions? Using Cognitive Interviews to Improve Surveys in Education Research. *Educational Evaluation and Policy Analysis , 26*, 1-22.

Devellis, R. F. (2012). *Scale Development: Theory and Applications* (3rd ed.). Thousand Oaks, CA: Sage.

Deyo, R. A., Diehr, P., & Patrick, D. L. (1991). Reproducibility and responsiveness of health status measures. Statistics and strategies for evaluation. *Controlled Clinical Trials, 12*(4 Suppl), 142S-158S.

Di Cicco-Bloom, B., & Crabtree, B. F. (2006). The qualitative research interview. *Medical Education , 40*, 314–321.

Dickey, L., Kagan , A., Lindsay, P., Fang, J., Rowland, A., & Black, S. (2010). Incidence and profile of inpatient stroke-induced aphasia in Ontario, Canada. *Archives of Physical Medicine and Rehabiliation , 91*, 196-201.

Dixon-Woods, M., Agarwal, S., Jones, D., Young, B., & Sutton, A. (2005). Synthesising qualitative and quantitative evidence: a review of possible methods. *Journal of Health Services, Research and Policy, 10* (1), 45-53.

Dixon-Woods, M., Ashcroft, R. E., Jackson, C. J., Tobin, M. D., Kivits, J., Burton, P. R., et al. (2007). Beyond "misunderstanding": written information and decisions about taking part in a genetic epidemiology study. *Social Science and Medicine, 65* (11), 2212-2222.

Doyle, P. J., McNeil, M. R., Mikolic, J. M., Prieto, L., Hula, W. D., Lustig, A. P., et al. (2004). The Burden of Stroke Scale (BOSS) provides valid and reliable score estimates of functioning and well-being in stroke survivors with and without communication disorders. *Journal of Clinical Epidemiology, 57*, 997-1007.

Draper, B., Bowring, G., & Thompson, C. (2007). Stress in caregivers of aphasic stroke patients: a randomized controlled trial. *Clinical Rehabiliation, 21*, 122-130.

Easterbrook, P. J., Berlin, J. A., Gopalan, R., & Matthews, D. R. (1991). Publication bias in clinical research . *Lancet, 337* (8746), 867-872.

Egger, M., & Davey Smith, G. (1998). Meta-analysis: Bias in location and selection of studies. *British Medical Journal, 316* (61-66).

Engelter, S. T., Gostynski, M., Papa, S., Frei, M., Born, C., Ajdacic-Gross, V., et al. (2006). Epidemiology of aphasia attributable to first ischemic stroke: Incidence, severity, fluency, etiology, and thrombolysis. *Stroke, 37*, 1379-1384.

Fabrigar, L. R., & Wegener, D. T. (2011). *Exploratory Factor Analysis*. Oxford, UK: Oxford University Press.

Fayed, N., Cieza, A., & Bickenbach, J. E. (2011). Linking health and health-related information to the ICF: A systematic review of the literature from (2001) to (2008) . *Disability and Rehabilitation, 33*(21-22), 1941-1951.

Fougeyrollas, P., Cloutier, R., Bergeron, H., Côté, J., Michel, G., & St. Michel, G. (1999). *The Quebec Classification: Disability Creation Process*. Lac St-Charles, Quebec: International Network on the Disability Creation Process.

Fox, L., Poulsen, S., Bawden, K. C., & Packard, D. (2004). Critical elements and outcomes of a residential family-based intervention for aphasia caregivers. *Aphasiology , 18*, 1177-1199.

Franzén-Dahlin, A., Laska, A. C., Larson, J., Wredling, R., Billing, E., & Murray, V. (2008). Predictors of life situation among significant others of depressed or aphasic stroke patients. *Journal of Clinical Nursing , 17* (12), 1574-1580.

Gagné, J. P. (1998). Reflections on evaluative research in audiological rehabilitation. *Scandinavian Audiology Supplementum, 49*, 69-79.

Gagné, J. P., Hétu, R., Getty, L., & McDuff, S. (1995). Towards the Development of Paradigms to Conduct Functional Evaluative Research in Audiological Rehabilitation. *Journal of the Academy of Rehabilitative Audiology, 28*, 7-25.

Geyh, S., Cieza, A., Schouten, J., Dickson, H., Frommelt, P., Omar, Z., et al. (2004). ICF core sets for stroke. *Journal of Rehabilitation Medicine, 44S*, 135-141.

Giddings, L. S., & Grant, B. M. (2007). A trojan horse for positivism? A critique of mixed methods research. *Advances in Nursing Science, 30*, 52-60.

Giddings, L., & Grant, B. (2009). From rigour to trustworthiness: Validating mixed methods. In S. Andrew, & E. Halcomb, *Mixed Methods Research for Nursing and the Health Sciences* (pp. 119-134). Oxford: Blackwell Publishing Ltd.

Gillespie, A., Murphy, J., & Place, M. (2010). Divergences of perspective between people with aphasia and their family members. *Aphasiology, 24*, 1559-1575.

Glogowska, M. (2011). Paradigms, pragmatism and possibilities: Mixed-methods research in speech and language therapy. *International Journal of Language and Communication Disorders, 46*, 251–260.

Graneheim, U., & Lundman, B. (2004). Qualitative content analysis in nursing research: Concepts, procedures and measures to achieve trustworthiness. *Nursing Education Today, 24*, 105-112.

Grawburg, M., Howe, T., Worrall, L., & Scarinci, N. (2012). A systematic review of the positive outcomes for family members of people with aphasia. *Evidence-Based Communication Assessment and Intervention, 6*, 135-149.

Grawburg, M., Howe, T., Worrall, L., & Scarinci, N. (2013a). Third-party disability in family members of people with aphasia—a systematic review. *Disability and Rehabilitation , 35* (16), 1324-1341.

Grawburg, M., Howe, T., Worrall, L., & Scarinci, N. (2013b). A qualitative investigation into third-party functioning and third-party disability in aphasia: Positive and negative experiences of family members of people with aphasia . *Aphasiology, 27* (7), 828-848.

Grawburg, M., Howe, T., Worrall, L., & Scarinci, N. (2013c). Describing the impact of aphasia on close family members using the ICF framework. *Disability and Rehabiliation*. Advance online publication. doi: 10.3109/09638288.2013.834984

Greenwood, N., Mackenzie, A., Cloud, G. C., & Wilson, N. (2008). Informal carers of stroke survivors – factors influencing carers: A systematic review of quantitative studies . *Disability and Rehabilitation, 30*, 1329-1349.

Greenwood, N., Mackenzie, A., Cloud, G. C., & Wilson, N. (2009). Informal primary carers of stroke survivors living at home-challenges, satisfactions and coping: a systematic review of qualitative studies. *Disability and Rehabilitation, 31* (5), 337-351.

Haley, W. E., Allen, J. Y., Grant, J. S., Clay, O. J., Perkins, M., & Roth, D. L. (2009). Problems and benefits reported by stroke family caregivers: Results from a prospective epidemiological study. *Stroke, 40* (6), 2129-2133.

Han, B., & Haley, W. B. (1999). Family caregiving for patients with stroke: Review and analysis. *Stroke, 30* (7), 1478-1485.

Hancock, A. (2011). Resources for families and clinicians. In L. Lapointe (Ed.), *Aphasia and Related Neurogenic Language Disorders* (pp. 211-219). New York, NY: Thieme.

Harris, D. (1989). Comparison of the 1-, 2-, and 3-parameter IRT models. *Educational Measurement: Issues and Practice, 8* (1), 35-41.

Helm-Estabrooks, N., & Albert, M. L. (2004). *Manual of Aphasia and Aphasia Therapy* (2nd ed.). Austin, TX: Pro-Ed.

Hemsley, G., & Code, C. (1996). Interactions between recovery in aphasia, emotional and psychosocial factors in subjects with aphasia, their significant others and speech pathologists. *Disability and Rehabiliation, 18*, 567-584.

Hemsley, B., Werninck, M., & Worrall, L. (2013). "That really shouldn't have happened": People with aphasia and their spouses narrate adverse events in hospital. *Aphasiology, 27*(6), 706-722.

Herrmann, M. (1997). Studying psychosocial problems in aphasia: Some conceptual and methodological considerations . *Aphasiology , 1*, 717-725.

Herrmann, M., Britz, A., Bartels, C., & Wallesch, C. (1995). The impact of aphasia on the patient and family in the first year poststroke. *Topics in Stroke Rehabiliation , 2*, 5-19.

Hétu, R., Jones, L., & Getty, L. (1993). The impact of acquired hearing impairment on intimate relationships: implications for rehabilitation . *Audiology, 32*, 363-381.

Hétu, R., Riverin, L., Lalande, N., Getty, L., & St-Cyr, C. (1988). Qualitative analysis of the handicap associated with occupational hearing loss. *British Journal of Audiology, 22*, 251-264.

Hilari, K., Northcott, S., Roy, P., Marshall, J., Wiggins, R. D., Chataway, J., et al. (2010). Psychological distress after stroke and aphasia: The first six months. *Clinical Rehabilitation, 24*, 181-190.

Holgado-Tello, H., Chacón–Moscoso, S., Barbero–García, I., & Vila-Abad, E. (2012). Polychoric versus Pearson correlations in exploratory and confirmatory factor analysis of ordinal variables. *Quality and Quantity, 44*, 153-166.

Holland, A., & Fridriksson, J. (2001). Aphasia management in the early phases of recovery following stroke. *American Journal of Speech-Language Pathology, 10*(1), 19-28.

Horn, J. L. (1965). A rationale and test for the number of factors in factor analysis. *Psychometrika, 30*, 179-185.

Howe, T. J., Worrall, L. E., & Hickson, L. (2008). Interviews with people with aphasia: Environmental factors that influence their community participation. *Aphasiology, 22*, 1092-1120.

Howe, T., Davidson, B., Worrall, L., Hersh, D., Ferguson, A., Sherratt, S., et al. (2012). "You needed to rehab . . . families as well": Family members' own goals for aphasia rehabilitation. *International Journal of Language and Communication Disorders, 47*, 511-521.

Hughes, J. C., Bamford, C., & May, C. (2008). Types of centredness in health care: themes and concepts. *Medicine, Health Care, and Philosophy, 11*(4), 455-463.

IBM Corp. (2010). *IBM SPSS Statistics for Mac*. Version 19.0. Armonk, NY: IBM Corp.

Jönsson, A. C., Lindgren, I., Hallström, B., Norrving, B., & Lindgren, A. (2005). Determinants of quality of life in stroke survivors and their informal caregivers. *Stroke, 36* (4), 803-808.

Johansson, M. B., Carlsson, M., & Sonnander, K. (2011). Working with families of persons with aphasia: a survey of Swedish speech and language pathologists. *Disability and Rehabilitation, 33*, 51-62.

Johnson, P. D. (1998). Rural stroke caregivers: A qualitative study of the positive and negative response to the caregiver role . *Topics in Stroke Rehabilitation, 5*(3), 51-68.

Kagan, A., & Kimelman, M. D. (1995). Informed consent in aphasia research: Myth or reality? *Clinical aphasiology, 23*, 65-75.

Kaiser, H. (1970). A second generation Little Jiffy. *Psychometrika, 35*, 401-415.

Kaiser, H. (1974). An index of factorial simplicity. *Psychometrika, 39*, 31-36.

Kaiser, H. (1960). The application of electronic computers to factor analysis. *Educational and Psychological Measurement, 20*, 141-151.

Kauhanen, M. L., Korpelainen, J. T., Hiltunen, P., Määttä, R., Mononen, H., Brusin, E., et al. (2000). Aphasia, depression, and non-verbal cognitive impairment in ischaemic stroke. *Cerebrovascular Disease, 10*, 455-461.

Kertesz, A. (2006). *Western Aphasia Battery-Revised*. San Antonio, Texas: Pearson.

King, R. B., & Shade-Zeldow, Y. (1995). Adaptation to stroke: Comparison of spouses of stroke survivors with and without aphasia. *Topics in Stroke Rehabilitation, 2*, 20-32.

Kinsella, G., & Duffy, F. (1978). The spouse of the aphasic patient. In G. Lebrun, & R. Hoops (Eds.), *The management of aphasia* (pp. 26-49). Amsterdam: Swets & Zeitlinger.

Kramer, B. J. (1997). Gain in the caregiving experience: Where are we? What next? . *Gerontologist, 7*, 218-232.

Krippendorff, K. (2004). *Content Analysis: An Introduction to its Methodology* (2nd ed.). Thousand Oaks, California: Sage Publications, Inc.

Kuo, D. Z., Houtrow, A. J., Arango, P., Kuhlthau, K. A., Simmons, J. M., & Neff, J. M. (2012). Family-Centered Care: Current Applications and Future Directions in Pediatric Health Care. *Maternal and Child Health Journal, 16*, 297-305.

Lai, J. S., & Eton, D. T. (2002). Clinically meaningful gaps. *Rasch Measurement Transaction, 15*, 580.

Landis, J., & Koch, G. (1977). The measurement of observed agreement for categorical data. *Biometrics, 33*, 159-174.

Lapointe, L. (2011). Humanistic basics: adaptation, accommodation, and artistos. In L. Lapointe (Ed.), *Aphasia and Related Neurogenic Language Disorders* (pp. 9-26). New York, NY: Thieme.

Law, J., Huby, G., Irving, A. M., Pringle, A. M., Conochie, C., Howorth, C., et al. (2010). Reconciling the perspective of practitioner and service user: findings from The Aphasia in Scotland study. *International Journal of Language and Communication Disorders, 45*, 551-560.

Le Dorze, G., & Brassard, C. (1995). A description of the consequence of aphaisa on aphasic persons and their relatives and close friends, based on the WHO model of chronic diseases. *Aphasiology, 9*, 239-55.

Le Dorze, G., & Signori, F. H. (2010). Needs, barriers and facilitators experienced by spouses of people with aphasia. *Disability and Rehabiliation, 32*, 1073-1087.

Le Dorze, G., Tremblay, V., & Croteau, C. (2009). A qualitative longitudinal case study of a daughter's adaptation process to her father's aphasia and stroke. *Aphasiology, 23*, 483-502.

Lemieux, L., Cohen-Schneider, R., & Holzapfel, S. (2001). Aphasia and sexuality. *Sex and Disability, 19*, 253–266.

Levack, W. M., Siegert, R. J., Dean, S. G., & McPherson, K. M. (2009). Goal planning for adults with acquired brain injury: How clinicians talk about involving family. *Brain Injury, 23*, 192-202.

Linacre, J. M. (2002). Optimizing rating scale category effectiveness. *Journal of Applied Measures, 3*, 85-106.

Linacre, J. M. (2004). Optimizing rating scale category effectiveness. In E. V. Smith, Jr, & R. M. Smith (Eds.), *Introduction to Rasch measurement* (pp. 258-278). Maple Grove, MN: JAM Press.

Linacre, J. M. (1994). Sample size and item calibration stability. *Rasch Measurement Transactions, 7*, 328.

Linacre, J. M. (2013). *Winsteps® Rasch measurement computer program User's Guide*. Beaverton, Oregon: Winsteps.com.

Linacre, J. M. (2012). Winsteps® Rasch measurement computer program. Beaverton, Oregon.

Lincoln, Y., & Guba, E. (1985). *Naturalistic inquiry*. London: Sage.

Long, A., Hesketh, A., & Bowen, A. (2009). Communication outcome after stroke: a new measure of the carer's perspective. *Clinical Rehabilitation, 23*, 846-856.

Lyons, R. F., Mickelson, K. D., Sullivan, M. J., & Coyne, J. C. (1998). Coping as a communal process. *Journal of Social and Personal Relationships, 15*, 579-605.

Ma, E. P.-M., Threats, T. T., & Worrall, L. E. (2008). An introduction to the International Classification of Functioning, Disability and Health (ICF) for speech-language pathology: Its past, present and future. *International Journal of Speech-Language Pathology, 10*, 2-8.

Mackenzie, A., & Greenwood, N. (2012). Positive experiences of caregiving in stroke: A systematic review. *Disability and Rehabilitation, 34*(17), 1413-22.

Mackenzie, A., Perry, L., Lockhart, E., Cottee, M., Cloud, G., & Mann, H. (2007). Family carers of stroke survivors: needs, knowledge, satisfaction and competence in caring . *Disability and Rehabilitation, 29* (2), 111-121.

Malone, R. L., Ptacek, P. H., & Malone, M. S. (1970). Attitudes expressed by families of aphasics. *The British Journal of Disorders of Communication, 5* (2), 174-179.

Marshall, R. C. (2002). Having the courage to be competent: persons and families living with aphasia. *Journal of Communication Disorders, 35*, 139-152.

Masala, C., & Petretto, D. R. (2008). From disablement to enablement: conceptual models of disability in the 20th century. *Disability and Rehabilitation, 30*, 1233-1244.

McCormack, J., McLeod, S., McAllister, L., & Harrison, L. J. (2009). A systematic review of the association between childhood speech impairment and participation across the lifespan. *International Journal of Speech-Language Pathology, 11*(2), 1754-9515.

McEwen, B. S. (2006). Protective and damaging effects of stress mediators: central role of the brain. *Dialogues in Clinical Neuroscience, 22*, 1092-1120.

McGurk, R., & Kneebone, I. I. (2013). The problems faced by informal carers to people with aphasia after stroke: A literature review. *Aphasiology, 27* (7), 765-783.

McGurk, R., Kneebone, I. I., & Pit ten Cate, I. M. (2011). "Sometimes we get it wrong but we keep on trying": A cross-sectional study of coping with communication problems by informal caregivers of stroke survivors with aphasia. *Aphasiology, 25*, 1507-1522.

McKee, K. J., Philip, I., Lamura, G., Prouskas, C., Oberg, B., Krevers, B., et al. (2003). The COPE index--a first stage assessment of negative impact, positive value and quality of support of caregiving in informal carers of older people. *Aging and Mental Health, 7* (1), 39-52.

McLeod, S. (2006). An holistic view of a child with unintelligible speech: Insights from the ICF and ICF-CY. *Advances in Speech-Language Pathology, 8* (3), 293-315.

Mertens, D. M. (2010). *Research and evaluation in education and psychology* (3rd ed.). Thousand Oaks, CA: Sage.

Michallet, B., Le Dorze, G., & Tétreault, S. (2001). The needs of spouses caring for severely aphasic persons. *Aphasiology, 15*, 731-747.

Michallet, B., Tétreault, S., & Le Dorze, G. (2003). The consequences of severe aphasia on the spouses of aphasic people: A description of the adaptation process. *Aphasiology, 17*(9), 835-859.

Minis, M. A., Heerkens, Y., Engels, J., Oostendorp, R., & van Engelen, B. (2009). Classification of employment factors according to the International Classification of Functioning, Disability and Health in patients with neuromuscular diseases: a systematic review. *Disability and Rehabiliation, 31*(26), 2150-2163.

Ministry of Social Development. (2008). *The New Zealand Carers' Strategy and Five-year Action Plan*. Available from: http://www.msd.govt.nz/about-msd-and-our-work/work-programmes/policy-development/carers-strategy/ Accessed: 22nd April, 2013.

Moore, L. W., Maiocco, G., Schmidt, S. M., Guo, L., & Estes, J. (2002). Perspectives of caregivers of stroke survivors: Implication for nursing. *Medsurg Nursing, 11* (6), 289-295.

Nätterlund, B. S. (2010). Being a close relative of a person with aphasia. *Scandinavian Journal of Occupational Therapy*, *17*, 18-28.

National Center for Medical Rehabilitation Research. (1993). *Research Plan for the National Center for Medical Rehabilitation Research*. Washington, D.C.: National Institutes of Health.

Nelson-Becker, H., Chapin, R., & Fast, B. (2009). The strengths model with older adults: Critical practice components. In T. s. practice, & D. Saleebey (Ed.), *The strengths model with older adults: Critical practice components* (5th ed., pp. 161–180). Boston: Pearson Education, Inc.

O'Connor, B. P. (2000). SPSS and SAS programs for determining the number of components using parallel analysis and Velicer's MAP test. *Behavior Research Methods, Instruments & Computers, 32*, 396-402.

Ozge, A., Ince, B., Somay, G., Erol, C. S., Uludu□z, D., Bulkan, M., et al. (2009). The caregiver burden and stroke prognosis. *Journal of Neurological Sciences , 26* (2), 139-152.

Pace, R., Pluye, P., Bartlett, G., Macaulay, A., Salsberg, J., Jagosh, J., et al. (2010). Reliability of a tool for concomitantly appraising the methodological quality of qualitative, quantitative and mixed meth- ods research: A pilot study. *38th Annual Meeting of the North American Primary Care Research Group (NAPCRG)*. Seattle.

Palmer, S., & Glass, T. A. (2003). Family Function and Stroke Recovery: A Review. *Rehabilitation Psychology*, *48*, 255-265.

Parag, V., Hackett , M. L., Yapa, C. M., Kerse, N., McNaughton, H., Feigin, V. L., et al. (2008). The impact of stroke on unpaid caregivers: Results from The Auckland Regional Community Stroke study, 2002–2003. *Cerebrovascular Diseases , 25*(6), 548-554.

Patton, M. Q. (2002). *Qualitative research and evaluation methods* (3rd ed.). Thousand Oaks, CA: Sage.

Pedersen, P., Vinter, K., & Olsen, T. (2004). Aphasia after stroke: type, severity and prognosis. *Cerebrovascular Disorders, 17*, 35-43.

Pierce, L. L., Steiner, V., Thompson, T., Govoni, A., & Friedemann, M. -L. (2007). Two sides to the caregiving story. *Topics in Stroke Rehabilitation, 14*(2), 13-20.

Pluye, P., Robert, E., Cargo, M., Bartlett, G., O'Cathain, A., Griffiths, F., et al. (n.d.). *Proposal: a mixed methods appraisal tool for systematic mixed studies reviews*. Retrieved September 20, 2012 from http://mixedmethodsappraisaltoolpublic.pbworks.com

Poland, B. (2001). Transcription quality. In *Handbook of Interview Research: Context and Method* (pp. 629-649). London: Sage Publications.

Pollock, A., St. George, B., Fenton, M., & Firkins , L. (2012). Top 10 research priorities relating to life after stroke - consensus from stroke survivors, caregivers, and health professionals. *International Journal of Stroke* .

Pope, A. M., & Tarlov, A. R. (Eds.). (1991). *Disability in America: A National Agenda for Prevention*. Washington, D.C.: National Academy Press.

Portney, L. G., & Watkins, M. P. (2009). *Foundations of Clinical Research: Applications to Practice* (3rd ed.). Upper Saddle River, NJ: Prentice-Hall.

Pound, C., Parr, S., & Duchan, J. (2001). Using partners' autobiographical reports to develop, deliver, and evaluate services in aphasia. *Aphasiology, 15* (5), 477-493.

Pring, T. (1999). Who cares for carers? *Aphasiology, 13* (12), 914-917.

Pringle, J., Hendry, C., McLafferty, E., & Drummond, J. (2010). Stroke survivors with aphasia: Personal experiences of coming home. *British Journal of Community Nursing, 15*, 241-247.

Rapp, S. R., & Chao, D. (2000). Appraisals of strain and gain: Effects on psychological wellbeing of caregivers of dementia patients. *Aging and Mental Health, 4*(2), 142-147.

Reed, G., Lux, J., Bufka, L., Trask, C., Peterson, D., Stark, S., et al. (2005). Operationalizing the international classification of functioning, disability and health in clinical settings. *Rehabilitation Psychology, 50*(2), 122–131.

Reinhard, S., Given, B., Petlick, N. H., & Bemis, A. (2008). Supporting Family Caregivers in Providing Care. In R. G. Hughes (Ed.), *Patient Safety and Quality: An Evidence-Based Handbook for Nurses* (pp. 341-404). Rockville, MD, USA: Agency for Healthcare Research and Quality.

Rice, B., Paull, A., & Muller, D. (1987). An evaluation of a social support group for spouses of aphasic partners. *Aphasiology, 1*, 247-256.

Rigby, H., Gubitz, G., & Philips, S. (2009). A systematic review of caregiver burden following stroke. *International Journal of Stroke, 4*, 285–292.

Rombough, R. E., Howse, E. L., & Bartfay, W. J. (2006). Caregiver strain and caregiver burden of primary caregivers of stroke survivors with and without aphasia. *Rehabilitation Nursing, 31*, 199-209.

Rombough, R. E., Howse, E. L., Bagg, S. D., & Bartfay, W. J. (2007). A comparison of studies on the quality of life of primary caregivers of stroke survivors: A systematic review of the literature. *Topics in Stroke Rehabilitation , 14*, 69-79.

Rose, T. A., Worrall, L. E., & McKenna, K. T. (2003). The effectiveness of aphasia-friendly principles for printed health education materials for people with aphasia following stroke. *Aphasiology , 17*(10), 947-963.

Ross, S., & Morris, R. (1988). Psychological adjustment of the spouses of aphasic stroke patients. *International Journal of Rehabilitation Research, 11*(4), 383-385.

Saleebey, D. (2009). Introduction: Power in the people. In D. Saleebey (Ed.), *The strengths perspective in social work practice* (5th ed., pp. 1-23). Boston, MA: Pearson Education, Inc.

Salonen, T. (1995). Report of a questionnaire survey of poststroke patients with aphasia and their families. *Topics in Stroke Rehabiliation, 2*, 72-75.

Sandelowski, M. (2000). whatever happened to qualitative description? *Research in Nursing & Health , 23*, 334-340.

Sandelowski, M., & Barroso, J. (2002). Finding the findings in qualitative studies. *Journal of Nursing Scholarship, 34* , 213–219.

Santos, M. E., Farrajota, M. L., Castro-Caldas, A., & de Sousa, L. (1999). Problems of patients with chronic aphasia: different perspectives of husbands and wives? *Brain Injury, 13*(1), 23-29.

Scarinci, N., Hickson, L., & Worrall, L. (2011). Third-party disability in spouses of older people with hearing impairment. *Perspective on Aural Rehabilitation and its Instrumentation, 18*, 3-12.

Scarinci, N., Worrall, L., & Hickson, L. (2012). Factors associated with third-party disability in spouses of older people with hearing impairment. *Ear and Hearing, 33*, 698-708.

Scarinci, N., Worrall, L., & Hickson, L. (2009). The ICF and third-party disability: Its application to spouses of older people wtih hearing impairment. *Disability and Rehabilitation, 31*, 2088-2100.

Schlosser, R. W., Wendt, O., & Sigafoos, J. (2007). Not all systematic reviews are created equal: Considerations for appraisal. *Evidence-Based Communication Assessment and Intervention , 1*(3), 138-150.

Schulz, R., Tompkins, C. A., & Rau, M. T. (1988). A longitudinal study of the psycho-social impact of stroke on primary support persons. *Psychology and Aging, 3*(2), 131-141.

Secrest, J. (2000). Transformation of the relationship: The experience of primary support persons of stroke survivors. *Rehabilitation Nursing, 25*(3), 93–99.

Servaes, P., Draper, B., Conroy, P., & Bowring, G. (1999). Informal carers of aphasic stroke patients: stresses and interventions. *Aphasiology, 13*, 889-928.

Sherratt, S., Worrall, L., Pearson, C., Howe, T., Hersh, D., & Davidson, B. (2011). "Well it has to be language-related": Speech-language pathologists goals for

people with aphasia and their families. *International Journal of Speech Language Pathology, 13*, 317-328.

Shyu, Y. I., Chen, M. C., Chen, S. T., Wang, H. P., & Shao, J. H. (2008). A family caregiver-oriented discharge planning program for older stroke patients and their family caregivers. *Journal of Clincial Nursing, 17*(18), 2497-2508.

Simmons-Mackie, N., & Kagan, A. (2007). Application of the ICF in aphasia. *28*, 244-253.

Simmons-Mackie, N., Raymer, A., Armstrong, E., Holland, A., & Cherney, L. R. (2010). Communication partner training in aphasia: a systematic review. *Archives of Physical Medicine and Rehabilitation, 91*(12), 1814-1837.

Simmons-Mackie, N., Threats, T. T., & Kagan, A. (2005). Outcome assessment in aphasia: a survey. *Journal of Communication Disorders, 38*, 1-27.

Sorin-Peters, R. (2004). The evaluation of a learner-centred training programme for spouses of adults with chronic aphasia using qualitative case study methodology. *Aphasiology, 18*(10), 951-975.

Sorin-Peters, R. (2003). Viewing couples living with aphasia as adult learners: Implications for promoting quality of life. *Aphasiology, 17*(4), 405-416.

Stephens, D., & Hétu, R. (1991). Impairment, disability and handicap in audiology: towards a consensus . *Audiology, 30*, 185-200.

Streiner, D. L. (1994). Figuring out factors: The use and misuse of factor analysis. *Canadian Journal of Psychiatry, 39*, 135-140.

Stroup, D. F., Berlin, J. A., Morton, S. C., Olkin, I., Williamson, G. D., Rennie, D., et al. (2000). Meta-analysis of observational studies in epidemiology: a proposal for reporting. Meta-analysis Of Observational Studies in Epidemiology (MOOSE) group. *The Journal of the American Medical Association, 283*(15), 2008-2012.

Subgranon, R., & Lund, D. A. (2000). Maintaining caregiving at home: A culturally sensitive grounded theory of providing care in Thailand. *Journal of Transcultural Nursing, 11*(3), 166-173.

Tabachnick, B. G., & Fidell, L. S. (2013). *Using multivariate statistics* (6th ed.). Upper Saddle River, NJ: Pearson Allyn & Bacon.

Tate, R. L. (2009). *A Compendium of Tests, Scales and Questionnaires*. London: Psychology Press.

Team, R. D. (2010). *R: A language and environment for statistical computing*. Vienna, Austria: R Foundation for Statistical Computing.

Tedeschi, R. G., & Calhoun, L. G. (2004). Posttraumatic growth: Conceptual foundations and empirical evidence . *Psychological Inquiry, 15*(1), 1-18.

Tedeschi, R. G., & Calhoun, L. G. (1996). The posttraumatic growth inventory: Measuring the positive legacy of trauma. *Journal of Traumatic Stress, 9*, 455-471.

Tennant, A., & Conaghan, P. G. (2007). The Rasch measurement model in rheumatology: what is it and why use it? When should it be applied, and what should one look for in a Rasch paper? *Arthritis & Rheumatism, 57*(8), 1358-1362.

Tennant, A., Penta, M., Tesio, L., Grimby, G., Thonnard, J. L., Slade, A., et al. (2004). Assessing and adjusting for cross-cultural validity of impairment and activity limitation scales through differential item functioning within the framework of the Rasch model: The PRO-ESOR project. *Medical Care, 42*, 37-48.

Thomas, D. (2003). A general inductive approach for qualitative data analysis. *The American Journal of Evaluation, 27*, 237-248.

Threats, T. (2007). Access for persons with neurogenic communication disorders: influences of personal and environmental factors of the ICF. *Aphasiology, 21*(1), 67-80.

Threats, T. (2010). The ICF framework and third party disability: Application to the spouses of persons with aphasia. *Topics in Stroke Rehabilitation , 17*(6), 451-457.

Threats, T. T. (2012). WHO's International Classification of Functioning, Disability, and Health: A Framework for Clinical and Research Outcomes. In L. Golper (Ed.), *Outcomes in Speech-Language Pathology: Contemporary Theories, Models, and Practices* (2nd ed., pp. 58-72). New York, NY: Thieme Medical Publishers, Inc.

Threats, T., & Worrall, L. (2004). Classifying communication disability using the ICF. *International Journal of Speech-Language Pathology , 6* (1), 53-62.

Toljamo, M., Perälä, M. L., & Laukkala, H. (2012). Impact of caregiving on Finnish family caregivers. *Scandinavian Journal of Caring Sciences, 26*(2), 211-218.

Tsouna-Hadjis, E., Vemmos, K. N., Zakopoulos, N., & Stamatelopoulos, S. (2000). First- stroke recovery process: the role of family social support . *Archives of Physical Medicine and Rehabilitation, 81*, 887.

Üstün, T. B., Chatterji, S., Bickenbach, J., Kostanjsek, N., & Schneider, M. (2003). The International Classification of Functioning, Disability and Health: a new tool for understanding disability and health . *Disability and Rehabilitation, 25*, 565-571.

van Heugten, C., Visser-Meily, A., Post, M., & Lindeman, E. (2006). Care for carers of stroke patients: evidence-based clinical practice guidelines. *Journal of Rehabilitation Medicine, 38*(3), 153-158.

Vecchio, N. (2008). Understanding the use of respite services among informal carers. *Australian Health Review, 32*, 459-467.

Velicer, W. F. (1976). Determiningthe number of components from the matrix of partial correlations . *Psychometrika, 41, 321-327*.

Velozo, C. A., Seel, R. T., Magasi, S., Heinemann, A. W., & Romero, S. (2012). Improving measurement methods in rehabilitation: core concepts and recommendations for scale development. *Archives of Physical Medicine and Rehabilitation, 93*(8Suppl), S154-163.

Verdonschot, M. M., de Witte, L. P., Reichrath, E., Buntinx, W. H., & Curfs, L. M. (2009). Impact of environmental factors on community participation of

persons with an intellectual disability: a systematic review. *Journal of Intellectual Disability Research, 53*(1), 54-64.

Visser-Meily, A., Post, M., Gorter, J. W., Berlekom, S. B., Van Den Bos, T., & Lineman, E. (2006). Rehabilitation of stroke patients needs a family-centred approach. *Disability and Rehabilitation, 28*, 1557-1561.

Visser-Meily, A., Post, M., Riphagen, I. I., & Lindeman, E. (2004). Measures used to assess burden among caregivers of stroke patients: a review. *Clinical Rehabilitation, 18*, 601-623.

Visser-Meily, A., Post, M., van de Port, I., Maas, C., Forstberg-Wärleby,, G., & Lindeman, E. (2009). Psychosocial functioning of spouses of patients with stroke from initial inpatient rehabilitation to 3 years poststroke: Course and relations with coping strategies. *Stroke, 40*, 1399-1404.

Vogt, D. S., King, D. W., & King, L. A. (2004). Focus groups in psychological assessment: Enhancing content validity by consulting members of the target population. *Psychological Assessment in the Public Domain, 16*(3), 231-243.

Wade, D., Hewer, R., David, R., & Enderby, P. (1986). Aphasia after stroke: Natural history and associated deficits. *British Medical Journal, 49*, 11-16.

White, C. L., Korner-Bitensky, N., Rodrigue, N., Rosmus, C., Sourial, R., Lambert, S., et al. (2007). Barriers and facilitators to caring for individuals with stroke in the community: the family's experience. *Canadian Journal of Neuroscience Nursing, 29*(2), 5-12.

White, C. L., Mayo, N., Hanley, J. A., & Wood-Dauphinee, S. (2003). Evolution of the caregiving expeirence in the initial 2 years following stroke. *Research in Nursing Health, 26*, 177-189.

WHO. (1980). *International Classification of Impairments, Disabilities and Handicaps: A Manual of Classification Relating to the Consequences of Diseases*. Geneva: World Health Organization.

WHO. (1990). *International Statistical Classification of Diseases and Related Health Problems (ICD-10)* (10th Revision ed.). Geneva: World Health Organization.

WHO. (2008). *The Global Burden of Disease: 2004 update*. Geneva: World Health Organization.

WHO. (2001). *The International Classification of Functioning, Disablity and Health, ICF*. Geneva: World Health Organization.

WHO. (2011). *World Report on Disability*. Geneva: World Health Organization.

Williams, S. E. (1993). The impact of aphasia on marital satisfaction. *Archives of Physical Medicine and Rehabilitation, 74*, 361-367.

Worrall, L. E. (2000). The influence of professional values on the functional communication approach in aphasia. In L. E. Worrall, & C. M. Frattali (Eds.), *Neurogenic Communication Disorders: A Functional Approach* (pp. 191-205). New York: Thieme.

Worrall, L. E., & Hickson, L. (2008). The use of the ICF in speech-language pathology research: Towards a research agenda. *International Journal of Speech-Language Pathology, 10*, 72-77.

Zemva, N. (1999). Aphasic patients and their families: Wishes and limits. *Aphasiology, 13*, 219-224.

# APPENDIX A

# THE REVISED 24-ITEM SIGNIFICANT OTHER SCALE FOR FAMILY MEMBERS OF PEOPLE WITH APHASIA

We are interested in finding out what it is like to have a family member with aphasia.

We are particularly interested in the effects of aphasia (the communication problem) rather than the stroke as a whole.

Please think about the statements below and circle the response that best describes how your family member's aphasia has affected you in the past month. We have included some examples to help you think about the question. Even if your situation is different than the example, the item may still apply to you.

---

1. Overall, the effect of my family member's **aphasia** on my life is:

| **-3** A complete problem | **-2** A moderate-substantial problem | **-1** A mild problem | **0** No change because of aphasia | **+1** A mild positive change | **+2** A moderate-substantial positive change | **+3** A complete positive change |
|---|---|---|---|---|---|---|

**HEALTH & DAILY LIFE**

2. Because of my family member's **aphasia** my own health has changed. For example, my health has improved, or I have developed a health condition, or an existing health condition has worsened (e.g., depression, ulcer, hypertension, etc.). For me this is:

| **-3** A complete problem | **-2** A moderate-substantial problem | **-1** A mild problem | **0** No change because of aphasia | **+1** A mild positive change | **+2** A moderate-substantial positive change | **+3** A complete positive change |
|---|---|---|---|---|---|---|

3. Because of my family member's **aphasia** my body's physical functioning has changed (e.g., changes in sleep, energy, weight loss/gain, etc.). For me this is:

| **-3** A complete problem | **-2** A moderate-substantial problem | **-1** A mild problem | **0** No change because of aphasia | **+1** A mild positive change | **+2** A moderate-substantial positive change | **+3** A complete positive change |
|---|---|---|---|---|---|---|

4. Because of my family member's **aphasia** I feel more/less stressed. For me this is:

| **-3** A complete problem | **-2** A moderate-substantial problem | **-1** A mild problem | **0** No change because of aphasia | **+1** A mild positive change | **+2** A moderate-substantial positive change | **+3** A complete positive change |
|---|---|---|---|---|---|---|

5. Because of my family member's **aphasia** I tend to be more/less emotional. For me this is:

| **-3** A complete problem | **-2** A moderate-substantial problem | **-1** A mild problem | **0** No change because of aphasia | **+1** A mild positive change | **+2** A moderate-substantial positive change | **+3** A complete positive change |
|---|---|---|---|---|---|---|

6. Because of my family member's **aphasia** my recreational activities have changed (e.g., time for myself, sports, hobbies, friends, relaxation, vacation, etc.). For me this is:

| **-3** A complete problem | **-2** A moderate-substantial problem | **-1** A mild problem | **0** No change because of aphasia | **+1** A mild positive change | **+2** A moderate-substantial positive change | **+3** A complete positive change |
|---|---|---|---|---|---|---|

7. Because of my family member's **aphasia** my social activities have changed (e.g., I socialise more/less often, more/less desire to socialise, socialise with/without family member with aphasia, etc.). For me this is:

| **-3** A complete problem | **-2** A moderate-substantial problem | **-1** A mild problem | **0** No change because of aphasia | **+1** A mild positive change | **+2** A moderate-substantial positive change | **+3** A complete positive change |
|---|---|---|---|---|---|---|

8. Because of my family member's **aphasia** I have experienced a change in my finances (e.g., income increase/decrease, increased spending, saved money, etc.). For me this is:

| **-3** A complete problem | **-2** A moderate-substantial problem | **-1** A mild problem | **0** No change because of aphasia | **+1** A mild positive change | **+2** A moderate-substantial positive change | **+3** A complete positive change |
|---|---|---|---|---|---|---|

9. Because of my family member's **aphasia** I have experienced changes to my paid or volunteer work (e.g., work fewer/more hours, took time off work, quit or changed job, stopped or started volunteering, etc.). For me this is:

| **-3** A complete problem | **-2** A moderate-substantial problem | **-1** A mild problem | **0** No change because of aphasia | **+1** A mild positive change | **+2** A moderate-substantial positive change | **+3** A complete positive change |
|---|---|---|---|---|---|---|

**ATTITUDE & PERSONAL LIFE**

10. Because of my family member's **aphasia** I feel more/less appreciative (e.g., appreciate that my family member lived through a stroke, appreciate my own health, appreciate life, etc.). For me this is:

| **-3** A complete problem | **-2** A moderate-substantial problem | **-1** A mild problem | **0** No change because of aphasia | **+1** A mild positive change | **+2** A moderate-substantial positive change | **+3** A complete positive change |
|---|---|---|---|---|---|---|

11. Because of my family member's **aphasia** my attitude has changed (e.g., I focus on the positive and keep things in perspective, I am less judgmental of others, I am more critical of the healthcare system, etc.). For me this is:

| **-3** A complete problem | **-2** A moderate-substantial problem | **-1** A mild problem | **0** No change because of aphasia | **+1** A mild positive change | **+2** A moderate-substantial positive change | **+3** A complete positive change |
|---|---|---|---|---|---|---|

12. Because of my family member's **aphasia** I have experienced personal changes (e.g., learned about myself, become stronger, learned to cope with a difficult situation, grew up quickly, etc.). For me this is:

| **-3** A complete problem | **-2** A moderate-substantial problem | **-1** A mild problem | **0** No change because of aphasia | **+1** A mild positive change | **+2** A moderate-substantial positive change | **+3** A complete positive change |
|---|---|---|---|---|---|---|

**HELPING OTHERS**

13. Because of my family member's **aphasia** I am the central source of social contact for him/her (e.g., I visit often, include him/her in my own social activities, take my family member on outings). For me this is:

| **-3** A complete problem | **-2** A moderate-substantial problem | **-1** A mild problem | **0** No change because of aphasia | **+1** A mild positive change | **+2** A moderate-substantial positive change | **+3** A complete positive change |
|---|---|---|---|---|---|---|

14. Because of my family member's **aphasia** I help my family member with speech therapy (e.g., I sit in on sessions with my family member, help my family member with speech therapy homework). For me this is:

| **-3** A complete problem | **-2** A moderate-substantial problem | **-1** A mild problem | **0** No change because of aphasia | **+1** A mild positive change | **+2** A moderate-substantial positive change | **+3** A complete positive change |
|---|---|---|---|---|---|---|

15. Because of my family member's **aphasia** I explain what aphasia is to others. For me this is:

| **-3** A complete problem | **-2** A moderate-substantial problem | **-1** A mild problem | **0** No change because of aphasia | **+1** A mild positive change | **+2** A moderate-substantial positive change | **+3** A complete positive change |
|---|---|---|---|---|---|---|

16. Because of my family member's **aphasia** I now help people with aphasia in my paid or volunteer work. For me this is:

| **-3** A complete problem | **-2** A moderate-substantial problem | **-1** A mild problem | **0** No change because of aphasia | **+1** A mild positive change | **+2** A moderate-substantial positive change | **+3** A complete positive change |
|---|---|---|---|---|---|---|

**COMMUNICATION & EMOTIONS**

17. Because of my family member's **aphasia** I feel more/less sad. For me this is:

| **-3** A complete problem | **-2** A moderate-substantial problem | **-1** A mild problem | **0** No change because of aphasia | **+1** A mild positive change | **+2** A moderate-substantial positive change | **+3** A complete positive change |
|---|---|---|---|---|---|---|

18. Because of my family member's **aphasia** I feel more/less worried. For me this is:

| **-3** A complete problem | **-2** A moderate-substantial problem | **-1** A mild problem | **0** No change because of aphasia | **+1** A mild positive change | **+2** A moderate-substantial positive change | **+3** A complete positive change |
|---|---|---|---|---|---|---|

19. Because of my family member's **aphasia** ease of communication with him/her has changed. For me this is:

| **-3** | **-2** | **-1** | **0** | **+1** | **+2** | **+3** |
|---|---|---|---|---|---|---|
| A complete problem | A moderate-substantial problem | A mild problem | No change because of aphasia | A mild positive change | A moderate-substantial positive change | A complete positive change |

20. Because of my family member's **aphasia** I have to communicate with my family member in a new or different way (e.g., I speak slowly, use shorter sentences, waits to give him/her time to find his/her words). For me this is:

| **-3** | **-2** | **-1** | **0** | **+1** | **+2** | **+3** |
|---|---|---|---|---|---|---|
| A complete problem | A moderate-substantial problem | A mild problem | No change because of aphasia | A mild positive change | A moderate-substantial positive change | A complete positive change |

21. Because of my family member's **aphasia** I help him/her to communicate with others (e.g., interpreting, using visual cues, helping him/her to understand and make decisions, etc.). For me this is:

| **-3** | **-2** | **-1** | **0** | **+1** | **+2** | **+3** |
|---|---|---|---|---|---|---|
| A complete problem | A moderate-substantial problem | A mild problem | No change because of aphasia | A mild positive change | A moderate-substantial positive change | A complete positive change |

**OUTSIDE INFLUENCES & INTERACTIONS**

22. Because of my family member's **aphasia** I feel more/less frustrated, angry, and annoyed. For me this is:

| **-3** A complete problem | **-2** A moderate-substantial problem | **-1** A mild problem | **0** No change because of aphasia | **+1** A mild positive change | **+2** A moderate-substantial positive change | **+3** A complete positive change |
|---|---|---|---|---|---|---|

23. Because of my family member's **aphasia** my friendships have changed (e.g., I have made new friends/lost touch with old friends, friends do not understand aphasia, need my friends more/less, see friends more/less, etc.). For me this is:

| **-3** A complete problem | **-2** A moderate-substantial problem | **-1** A mild problem | **0** No change because of aphasia | **+1** A mild positive change | **+2** A moderate-substantial positive change | **+3** A complete positive change |
|---|---|---|---|---|---|---|

24. Because of my family member's **aphasia** I have experienced changes to my education and/or learning. (e.g., changed type of training, learned more about aphasia, stroke, and caregiving, etc.). For me this is:

| **-3** A complete problem | **-2** A moderate-substantial problem | **-1** A mild problem | **0** No change because of aphasia | **+1** A mild positive change | **+2** A moderate-substantial positive change | **+3** A complete positive change |
|---|---|---|---|---|---|---|

# APPENDIX B

# AUTHOR COPYRIGHT PERMISSIONS FOR PUBLISHED WORKS INCORPORATED INTO THE THESIS

---

1. Author copyright permissions for Francis & Taylor (publisher of *Aphasiology* and *Evidence-Based Communication Assessment and Intervention*). Retrieved September 30, 2013, from http://journalauthors.tandf.co.uk/permissions/reusingOwnWork.asp

> "*In assigning Taylor & Francis or the journal proprietor copyright, or granting an exclusive license to publish, you retain:*
>
> *…the right to include an article in a thesis or dissertation that is not to be published commercially, provided that acknowledgment to prior publication in the journal is made explicit…"*

This permission is applicable to the following included papers:

Grawburg, M., Howe, T., Worrall, L., & Scarinci, N. (2012). A systematic review of the positive outcomes for family members of people with aphasia. *Evidence-Based Communication Assessment and Intervention, 6*(3), 135-149.

Grawburg, M., Howe, T., Worrall, L., & Scarinci, N. (2013). A qualitative investigation into third-party functioning and third-party disability in aphasia: Positive and negative experiences of family members of people with aphasia. *Aphasiology, 27*(7), 828-848.

2. Author copyright permissions for Informa (publisher of *Disability and Rehabilitation*). Retrieved September 30, 2013, from http://comms.informahealthcare.com/what-we-do/publication-support/permissions/

> "*If you are an author seeking to reuse your own work, you may already be covered by your Copyright Transfer Agreement (CTA).*
>
> *The CTA covers most non-commercial uses of your content, including submitting your thesis to an institutional repository. If your intended use is covered by the CTA, you do not need to apply for permission."*

This permission is applicable to the following included papers:

Grawburg, M., Howe, T., Worrall, L., & Scarinci, N. (2013). Third-party disability in family members of people with aphasia – A systematic review. *Disability and Rehabilitation, 35(16):*1324-41.

Grawburg, M., Howe, T., Worrall, L., & Scarinci, N. (2013). Describing the impact of aphasia on close family members using the ICF framework. *Disability and Rehabilitation*. doi: 10.3109/09638288.2013.834984